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ABSTRACT

Presented are proceedings from a conference aimed at clarifying issues regarding education for the severely multiply handicapped, outlining goals, and producing 1-year timelines for Idaho, Utah, Montana, Wyoming, and the nation-at-large. Reported are the goals and implementation strategies (such as designing and implementing statewide programs to increase acceptance attitudes of professionals toward parents and their severely handicapped children) developed in workshops focusing on the areas of systematic delivery systems, identification of constraints, options for unserved children, relevant education, and parent education. One-year timelines for implementation of goals in each of the latter areas are included. Appendixes contain the texts of speeches, keynote addresses, and thematic statements; a diagram of the workshop structure; a conference evaluation report; and a directory of participants. (GW)

U.S. DEPARTMENT OF HEALTH,
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION



THE PROCEEDINGS FROM THE
REGIONAL, TOPICAL CONFERENCE

the severely, multiply handicapped

what are the issues?

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DEPARTMENT OF SPECIAL EDUCATION,
UNIVERSITY OF UTAH

MARCH 6-8, 1974, SALT LAKE CITY, UTAH

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GUIDE TO INITIALS

AAMD	American Association on Mental Deficiency
ACLD	Association for Children with Learning Disabilities
ALRC	Associate Learning Resource Center (formerly Regional SEIMC)
ARC	Association for Retarded Citizens
BEH	Bureau of Education for the Handicapped
CEC	Council for Exceptional Children
DDD	Division for Developmental Disabilities
EHA	Education of the Handicapped Act
ESEA	Elementary and Secondary Education Act
ERIC	Education Resources Information Center
HEW	Health, Education and Welfare
IEA	Intermediate education agency
LEA	Local education agency
LRC	Learning resource center (formerly SEIMC)
NASDSE	National Association of State Directors of Special Education
RMRRC	Rocky Mountain Regional Resource Center
RRC	Regional Resource Centers
SEA	State education agency
SEIMC	see ALRC
UAF	University affiliated facility
UCP	United Cerebral Palsy

THE SEVERELY, MULTIPLY HANDICAPPED – WHAT ARE THE ISSUES?

In April, 1973, at a meeting in Coeur d'Alene, Idaho, the Rocky Mountain Regional Resource Center (RMRRC) asked the State Directors of Special Education (from Idaho, Montana, Utah and Wyoming) to list and then prioritize the needs of their states that were within the scope of technical assistance which the RMRRC could deliver. High on all four lists was the need to know more about service delivery to the severely, multiply handicapped.

The discussions that day about the needs of the severely, multiply handicapped raised many pertinent questions: How do you define the target population? What kinds of services should school systems deliver? How can you serve a severely, multiply handicapped child who lives in a remote rural area? Are there successful programs under way now? What funds are available to states? What services do we now have that we could better utilize to serve this population? How do you get the public to support the kinds of services needed?

There was also discussion about how the RMRRC's technical assistance might produce the most significant impact on all four states, and in the most fiscally responsible manner. It was decided that a working conference would provide the technical assistance with the most potential.

So planning began, on that day, for a regional topical conference. The theme, "The Severely Multiply Handicapped: What Are The Issues?" speaks to the questions raised then and in later planning meetings. The five topical areas which the conference emphasized were also defined by compiling and prioritizing topics requested by the State Directors. They are:

- Systematic Delivery System
- Identification of Constraints
- Options for Unserved Children
- What is Relevant Education
- Parent Education: Their Role

The states emphasized that they needed more than just printed or verbal information. They wanted to come away from the conference with some concrete first steps, tailor-made to fit into the existing state structures.

If the states' requests were to be met, the conference would have to be tightly organized, involve people from across the four states, and utilize the best resources available. A handful of leaders were identified—people from across the nation who are forerunners in serving the severely, multiply handicapped. They were

each contacted, and agreed to lead workshops where they could help incorporate their wisdom and insight into the goals, strategies and tactics that each workshop would produce.

As plans proceeded, news of the working conference spread. Requests for information began arriving at the RMRRC from across the country. When the four State Directors stated their need to know how to best serve the severely handicapped, they were articulating an emerging national need. For parents, teachers and administrators, excitement and expectations about the conference began to grow.

The conference on the severely, multiply handicapped actually began in Coeur d'Alene a year ago. From the beginning, the RMRRC planned to compile the conference information in a way that would make it useful not only to participants, but also to those who were unable to attend. This document, then, is the final step.

The information presented here reflects the dedicated labor of the 257 people who attended the conference. While most of them came from the four RMRRC states, a total of 18 states and the District of Columbia were represented at the conference.

As you read through the following pages, keep in mind the conference objectives:

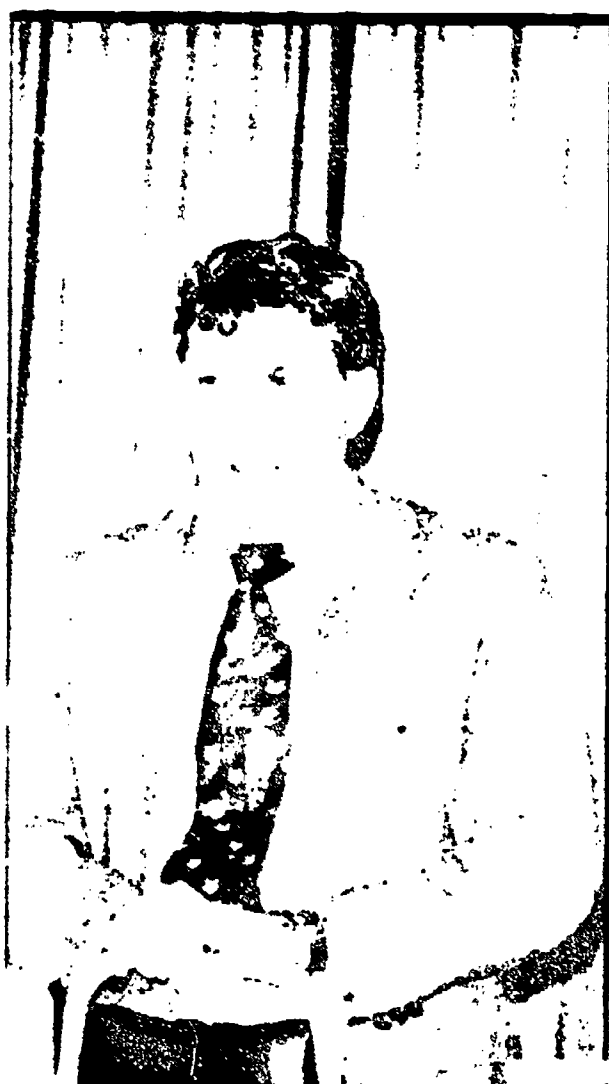
Conference Goal: To provide meaningful technical assistance to states.

1. Clarify issues regarding education for the severely, multiply handicapped.
2. Outline first action steps.
3. Produce one-year timelines for each state in the RMRRC region on each topic.

Brief explanations precede each section of the document. We hope the enclosed information will help anyone who is searching to take the first steps in serving the severely, multiply handicapped.

SCHEDULE										CONFERENCE ON THE SEVERELY MULTIPLY HANDICAPPED										S.L.C.										
WEDNESDAY MARCH 6					THURSDAY MARCH 7					FRIDAY MARCH 8																				
HOUR		EVENT			HOUR		EVENT			HOUR		EVENT			HOUR		EVENT													
9:00-9:30		Conference Opening			9:00-10:00		Keynote Address Mr. Fred Krause			9:00-10:00		Keynote Address Mr. Francis Lynch			9:00-10:00		Keynote Address Mr. Francis Lynch													
9:30-10:30		Keynote Address: Dr. R. Paul Thompson			10:00-12:00		Workshops by themes (same groups)			10:00-12:00		Workshops by themes (same groups)			10:00-11:30		States workshop on application													
10:30-12:00		Thematic Statements 1. Sherr 2. Berkowitz 3. Helzel 4. Brown 5. Ruess					Thematic Statements 1. Sherr 2. Berkowitz 3. Helzel 4. Brown 5. Ruess					Thematic Statements 1. Sherr 2. Berkowitz 3. Helzel 4. Brown 5. Ruess					Thematic Statements 1. Sherr 2. Berkowitz 3. Helzel 4. Brown 5. Ruess													
12:00-1:30		Lunch by States State Directors hosting			12:00-2:00		Lunch by workshops (working lunch)			12:00-2:00		Lunch by workshops (working lunch)			12:00-1:30		Banquet Dr. Robert Erdman, host													
1:30-4:30		Seminars by themes			2:30-4:30		Keynote Dialogue			2:30-4:30		Keynote Dialogue			12:00-1:30		Conference Closing Symbolic Reports by States Send Out													
		1 2 3 4 5					1 2 3 4 5					1 2 3 4 5					1 2 3 4 5													
		Sherr			Thompson		Krause			Lynch						Idaho			Montana			Wyoming			Utah			National		
4:30-5:30		No Host Hospitality Bar			4:30-5:30		No Host Hospitality Bar																							
5:30-7:30		Free time (dine at own choice)			5:30-7:30		Free time (dine at own choice)																							
7:30-10:00		Workshops by themes (same groups)			7:30-10:00		Workshops by themes (same groups)																							
		1 2 3 4 5					1 2 3 4 5																							
		Sherr			Berkowitz		Helzel			Brown		Ruess																		

THE KEYNOTERS



R. Paul Thompson, M.A.

Mr. Thompson is the Chairman of the Task Force on Severely Handicapped Children and Youth, Bureau of Education for the Handicapped, Washington, D.C.



Edwin W. Martin, Ph.D.

Dr. Martin is Associate Commissioner, Bureau of Education for the Handicapped, Washington, D.C.



Fred J. Krause, M.Ed.

Mr. Krause is Executive Director of the President's Committee on Mental Retardation, Washington, D.C.



Francis X. Lynch, M.Ed.

Mr. Lynch is Director of the Division of Developmental Disabilities, Washington, D.C.



THE WORKSHOPS

After the opening ceremonies and the first keynote speech, all participants met in state groups. Those who attended the conference, but who came from states other than Idaho, Montana, Utah or Wyoming, met in the nation-at-large group. The state groups were hosted by the State Directors of Special Education or their representatives and Robert L. Erdman, Chairman, Department of Special Education, University of Utah, hosted the national group. The hosts for the states groups were, for Idaho: John Comba, Judy Schrag; Montana: Michael Fredrickson; Utah: Ben Bruse, Geraldine Clark, Randolph Sorensen; Wyoming: Lamar Gordon, Jr., Thomas McCartney, Charles Vanover Jr.



At this first meeting, each participant chose one of the five workshop groups with the understanding he would continue with that same group for all working sessions. The participants then attended four workshops to build a tactical model in the specific area (e.g., Systematic Delivery System).



On the final day of the conference, the participants again met by states. This meant that each state group held members who had participated in all five workshops. They then produced state timelines for each topical area.

In the workshops, the participants learned that they possess the resources that will be needed if we are to make a significant difference in services for the severely, multiply handicapped. Those who attended this working conference really did work—even through lunch and till 10:00 p.m. at night!



The same general format was used by each workshop leader (Appendix B), but the leaders were invited to innovate within the structure if that seemed advisable. Thus, the form of each workshop varies somewhat. The information that follows is unedited, as the spontaneity and real value of the work might have been lost had the work been edited for conformity.



1. SYSTEMATIC DELIVERY SYSTEM

Resource Person: Richard Sherr, Ed.D.

Dr. Sherr is Director of Special Education Services, Lancaster-Lebanon Intermediate Unit B, Lancaster, Pennsylvania.

His thematic statement is located in Appendix A

Recorders: Mike Hardman, Kris Welling



Overall Goal

To provide services to all severely, multiply handicapped children within the state through a systematic delivery system.

GOAL 1.0 DETERMINE PHILOSOPHY, POPULATION TO BE SERVED, LAWS AND REGULATIONS, ROLES AND RESPONSIBILITIES, TO PROVIDE SERVICES TO ALL SEVERELY MULTIPLY HANDICAPPED CHILDREN

Strategy 1.1 Establish a favorable attitude and philosophy among the deliverers of service and those who will receive or benefit from services

Tactic 1.1.1 Promote discussion of the issues among professionals, special educators, state department officials, school administrators, parents of handicapped children and personnel of other agencies

1.1.2 Articulate a philosophy that is agreeable to those who will provide and receive services

Strategy 1.2 Entrust local school districts with responsibility to identify the population that requires service

Tactic 1.2.1 Inquire about children with local welfare or service agencies

1.2.2 Organize a publicity program that will make people aware of the intention to provide service, and encourage them to report the existence of children needing service

Strategy 1.3 A task force committee composed of providers and consumers of potential services should review the laws and regulations to determine if they permit the state to act according to its philosophy



Tactic 1.3.1	Recommend necessary changes
1.3.2	Have parents informed of legal issues in order to secure their support
<u>Strategy 1.4</u>	Identify the specific responsibilities of each person involved in providing the service
Tactic 1.4.1	State department
1.4.2	School districts
1.4.3	Legislators
1.4.4	Institutions
1.4.5	Parents
1.4.6	Other agencies
1.4.7	Parent and professional organizations
1.4.8	Federal people
GOAL 2.0	TO SPECIFY PERSONNEL, PROGRAMS, FACILITIES, COSTS, TO PROVIDE SERVICES TO ALL SEVERELY MULTIPLY HANDICAPPED CHILDREN
<u>Strategy 2.1</u>	Determine the total personnel needs
Tactic 2.1.1	Identification of target <ul style="list-style-type: none"> A. IEA B. Other agencies C. Media (electronic, print, etc.) D. Identification of service patterns
2.1.2	Identification of existing personnel by disciplines <ul style="list-style-type: none"> A. Survey IEAs B. Survey SEAs C. Survey all other agencies
2.1.3	Determine training needs (see 1 and 2)
<u>Strategy 2.2</u>	What programs do we need
Tactic 2.2.1	Describe existing programs
2.2.2	Describe new programs needed
<u>Strategy 2.3</u>	Determine extent of facilities
Tactic 2.3.1	List existing facilities
2.3.2	Additional facilities needed: locate, establish
<u>Strategy 2.4</u>	Determine costs—overall
Tactic 2.4.1	Current financing

2.4.2	Future financing needed--projected
GOAL 3.0	IMPLEMENT SERVICES FOR ALL SEVERELY MULTIPLY HANDICAPPED CHILDREN
<u>Strategy 3.1</u>	Establish goals for systematic delivery system
Tactic 3.1.1	Delineate preliminary goals (based on needs assessment) and present to parent and/or professional groups for refinement
<u>Strategy 3.2</u>	Development of alternative models for systematic delivery
Tactic 3.2.1	Review existing delivery models
3.2.2	Make recommendations for pilot programs
3.2.3	Provide technical assistance for implementation of pilot programs
3.2.4	Promote chosen program
3.2.5	Lobby for enabling legislation A. Mandate B. Funds
3.2.6	Seek provisions for other funds
GOAL 4.0	TO DEVELOP A MEANS OF ASSESSING THE CAPABILITY OF SERVICES TO MEET THE THE NEEDS SYSTEMATICALLY
<u>Strategy 4.1</u>	Have all the severely handicapped been identified?
Tactic 4.1.1	Census
4.1.2	Social services and other
<u>Strategy 4.2</u>	Are individual needs of student being met?
Tactic 4.2.1	Assessment tool (criterion measure)
4.2.2	Timelines (periodic evaluation)
<u>Strategy 4.3</u>	Needs assessment update
Forces:	(for above goals, strategies and tactics) State, national, regional , local, private agencies (to be identified by state) ARCs, other parent organizations Task forces Advisory boards Outside consultants Teacher organizations Private physicians Public health Department of Welfare



Ethnic council
Civic groups
Churches
State mental health/mental retardation
Bureau of Vocational Rehabilitation

Tools: (for above goals, strategies and tactics)

Search materials
Newspapers
TV, telephone, (public media)
Word of mouth
School census
Questionnaires
Evaluation institutions
Data banks (e.g., ERIC)
Curriculum guides
Instructional materials
Equipment
Consultants
Physicians
Workshops
In-service programs
Various support services
ALRCs
RRCs



2. IDENTIFICATION OF CONSTRAINTS ON GETTING CHILDREN SERVED

Resource Person: Albert J. Berkowitz, Ed.D.

Dr. Berkowitz is Deputy Assistant Commissioner for Mental Retardation, Department of Mental Health, Commonwealth of Massachusetts.

His thematic statement is located in Appendix A.

Recorders: Ann Leming, Elizabeth Vigeon



CONSTRAINT: Inadequate interdisciplinary and intradisciplinary interchange

GOAL 1.0 PROVIDE STRUCTURE IN WHICH PROFESSIONALS OF VARIOUS DISCIPLINES CAN COME TOGETHER AND ESTABLISH A COMMON SET OF PRIORITIES

Strategy 1.1 In-service training for inter- and intradisciplinary staff (to include district staff)

Tactic 1.1.1 Recruit and select in-service training team
A. Conduct survey of professionals' attitudes and needs

Tools: In-service curriculum; sales pitch for in-service

Technical Assistance: RRC, ALRC

Evaluation: 75% of participating professionals agree on their top priorities

Strategy 1.2 Conferences (include administrators) specifically to set priorities for local area concerning the multiply handicapped

Tactic 1.2.1 Contact all relevant agencies to establish date and secure their participation
A. Establish leadership for conference

Tools: Questionnaire for survey of attitudes/needs; promotion propaganda for conference

Technical Assistance: School counselors (key implementors); State Departments of Education; local school administrators

CONSTRAINT: Inadequate interdisciplinary and intradisciplinary interchange

GOAL 2.0 ADOPT A CURRICULUM AND NEW VIEWS TOWARD THE MULTIPLY HANDICAPPED WHICH INCORPORATE A COMMON TERMINOLOGY



<u>Strategy 2.1</u>	Establish a plan in universities which would enable various disciplines to share curriculum relevant to the severely multiply handicapped
Tactic 2.1.1	Contact Deans of various schools in various disciplines to meet and draw plans for curriculum sharing A. Prepare a proposal to be presented to Deans concerning curriculum sharing
Tools:	Developed curriculum for universities
Technical Assistance:	State Board of Higher Education; university department chairpersons (key implementors)
Evaluation:	If Deans met, agreed on curriculum sharing, and established a curriculum for use in their programs
<u>Strategy 2.2</u>	In-service training program on interdisciplinary level
Tactic 2.2.1	In multi-disciplined agencies, in-service rotation of disciplines (two-week model) A. In single-discipline agencies, have a cross-exchange between disciplines
Tools:	Glossary of terminology for interdisciplinary professionals; two-week rotation model for interdisciplinary in-service
Technical Assistance:	Local agency and school administrators; university department heads of special education

CONSTRAINT: Lack of public awareness of the needs of the multiply handicapped

GOAL 3.0 TO RAISE THE LEVEL OF COMMUNITY AWARENESS REGARDING MULTIPLY HANDICAPPED PERSONS SO THAT PEOPLE RECOGNIZE THE RIGHT OF HANDICAPPED PERSONS TO AN APPROPRIATE INTERVENTION TOWARD PERSONAL DIGNITY AND POTENTIAL

<u>Strategy 3.1</u>	Agencies will request technical assistance pertinent to awareness from regional centers, e.g., RRCs, ALRCs
Tactic 3.1.1	Identify by national, state and local levels, existing resources (agencies, programs, individuals) which may contribute to awareness campaign
3.1.2	Conduct workshops on how to tap these resources; obtain approved, effective literature to be used in campaign

3.1.3	Select and use appropriate agencies and resources for application to local problems dealing with awareness
<u>Strategy 3.2</u>	LEA special education personnel, informed of services for the severely multiply handicapped, will inform other special educators, regular education teachers and ancillary personnel of services to that handicapped population
Tactic 3.2.1	Develop or acquire a multi-media presentation appropriate to that handicapped population.
3.2.2	Conduct training/workshops, or whatever method is appropriate for target population, to present this multi-media package
3.2.3	Use package in sectional meetings in state conventions of professional organizations
<u>Strategy 3.3</u>	Include medical profession in campaign for awareness of the severely multiply handicapped as human beings
Tactic 3.3.1	Locate sympathetic medical person who will infiltrate the local profession and arrange for a presentation of the package
3.3.2	Place literature in medical centers, doctors' offices, etc.
<u>Strategy 3.4</u>	Include churches, etc., in campaign
Tactic 3.4.1	Contact local ministerial council and arrange for presentation, placement of literature
3.4.2	Include youth groups or other church organizations for presentations, etc.
<u>Strategy 3.5</u>	Include PTA
Tactic 3.5.1	Identify exceptional child chairman of PTA
3.5.2	Arrange for presentation to PTA
<u>Strategy 3.6</u>	Include university groups: e.g., sororities, etc.
Tactic 3.6.1	Arrange for meeting with Panhellenic League
3.6.2	Organize planning and training session to include interested persons; give presentation
<u>Strategy 3.7</u>	Include civic groups: e.g., Lions, Rotary, etc.
Tactic 3.7.1	Identify responsible club officer
3.7.2	Arrange presentation to group
<u>Strategy 3.8</u>	Utilize volunteer programs, such as foster grandparents, etc.

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- Tactic 3.8.1 Contact local volunteer groups; plan meetings
- 3.8.2 Identify individuals who seem prepared to respond to their new awareness with action
- 3.8.3 Organize a volunteer program (individual training, placement, evaluation, follow-up)
- Strategy 3.9 Utilize handicapped students as teachers and aides
- Tactic 3.9.1 Engage students to help implement strategies 4.1 and 4.8
- Strategy 3.10 Utilize elementary school peers as "special friends" or advocates for severely handicapped children
- Tactic 3.10.1 Select pairs and match
- 3.10.2 Control activities to avoid exploitation of either severely, handicapped or regular children.
- Strategy 3.11 Present special community-wide programs to demonstrate abilities of severely handicapped children
- Tactic 3.11.1 Seek out special abilities of interest to general public.
- 3.11.2 Organize events to display these talents, again avoiding exploitation

CONSTRAINT: Cost involved in providing services to the severely handicapped

GOAL 4.0 CLARIFY, MODIFY AND SYSTEMATIZE BUDGETS RELATIVE TO PROVIDING ADE- QUATE SERVICES FOR THE SEVERELY MULTIPLY HANDICAPPED

- Strategy 4.1 Clarify existing funding mechanisms
- Tactic 4.1.1 Designate a specialist in grant writing and convince funding sources of the need to modify strategies which prove ineffective in accomplishing stated objectives
- Strategy 4.2 Develop fiscal and program accountability
- Tactic 4.2.1 Develop tools such as program or activities report for fiscal accountability; develop a cost allocation plan with a line-item budget
- Strategy 4.3 Provide resource personnel who can assist in advocacy of existing programs for the handi- capped



Tactic 4.3.1	State Department of Education plans and conducts a series of workshops with appropriate agency administrators, teachers, fiscal managers, evaluators, citizens and handicapped persons
<u>Strategy 4.4</u>	Systematically collect and disseminate available information for fiscal funding to appropriate legislators, state agencies, local government units
Tactic 4.4.1	Designate a specialist in grant writing and convince funding sources of the need to modify strategies which prove ineffective in accomplishing stated objectives
<u>Strategy 4.5</u>	Establish a system for identifying handicapped children in and out of school who are not receiving appropriate services
Tactic 4.5.1	Establish a system for identifying currently unserved and underserved children; utilize a viable model for the state's characteristics, such as the model presently in use in Casper, Wyoming (Council of Social Services)
<u>Strategy 4.6</u>	Sharing of knowledge and techniques by professionals and parents to jointly determine priorities
Tactic 4.6.1	Establish a communication process that will insure mutual understanding of the program, the target group, and the method of reaching goal
<u>Strategy 4.7</u>	Increase opportunities for interagency cooperation
Tactic 4.7.1	Work with appropriate agencies, administrators to determine role each has with regard to program area, fiscal management area, evaluation and monitoring
<u>Strategy 4.8</u>	Identify implementors for 7 strategies above
Tactic 4.8.1	Identify professional administrative staff members who could help implement above strategies
4.8.2	Identify funding agencies
4.8.3	Identify consultants who could help implement above strategies: i.e., legislators, handicapped individuals, parents, teacher/trainers, citizen advisory groups
Evaluation:	Evaluation of above strategies will be contained in the measurable goals and objectives



CONSTRAINT: Bureaucracy is a barrier to service delivery

GOAL 5.0 TO BRING INFLUENTIAL REPRESENTATIVE GROUPS TOGETHER IN ORDER TO INFLUENCE THE BUREAUCRACY TO PROVIDE ADEQUATE SERVICES

Strategy 5.1 Form coalition of interest groups—consumers and providers

Strategy 5.2 Schedule regular ongoing legislative committee meetings with providers of special services

Strategy 5.3 Increase number of providers on decision-making boards

Tactics: (for above 3 strategies)
1. Identify interested groups
2. Form conferences for assembling leaders; develop an ad hoc committee by some means (through CEC, ARC, school systems, advisory boards, etc.)

Forces: (for strategies and tactics above)
1. Leaders identified above instigate organized action through the interested groups in local, regional and statewide efforts
2. Local workshops develop information and action on:
A. Knowledge of issues
B. Lobbying
C. Publicity: use of media to develop awareness
 . to get individuals to write to bureaucrats, etc.
 . to get commitment from individuals to work in united effort

Evaluation Strategies: (for strategies and tactics above)
1. Is the coalition of leaders of the interest groups functioning?
2. Have specific plans been made for organization of workshops on regional or local levels?
3. Have pamphlets been published to disseminate information?
4. Have citizens written congressmen?
5. Have lobbyists exerted influence on politicians?
6. Are local interest groups working in cooperative efforts?

3. OPTIONS FOR THE UNSERVED CHILDREN

Resource Person: Elsie D. Helsel, Ph.D.

Dr. Helsel is the Washington Representative for United Cerebral Palsy.

Her thematic statement is located in Appendix A.

Recorders: Joan Anderson, Brent Pitt



GOAL 1.0 EXPAND EXISTING PROGRAMS, APPROPRIATE TO THE NEEDS OF SEVERELY HANDICAPPED CHILDREN

Strategy 1.1 Obtain an index of existing services and a general description of each—both public and private

Tactic 1.1.1 Contact state and local agencies—both public and private

1.1.2 Obtain program descriptions and entrance requirements

1.1.3 Compile findings and publish

1.1.4 Disseminate

1.1.5 Establish a means to keep information up to date

1.1.6 Establish inter-agency communication

Implementation: Index of existing services to be published by SEA staff

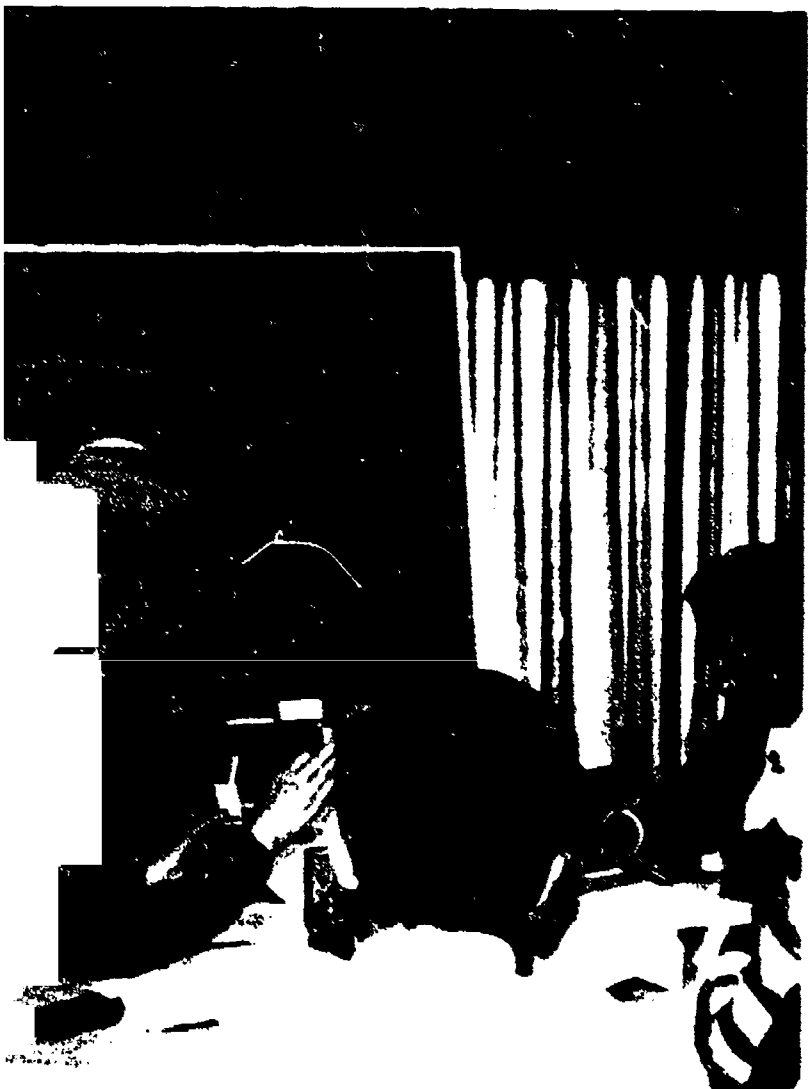
Strategy 1.2 Establish evaluation criteria for existing programs relative to children's needs

Tactic 1.2.1 Prepare a list of evaluation indices using:
A. State guidelines
B. Published and private agency input
C. Health and safety factors
D. Staff competency guidelines
E. Consulting expertise
F. Parent input

1.2.2 Establish a needs assessment team to apply above indices

1.2.3 Establish an accreditation team

Implementation: 1. Establish a Governor's Advisory Committee for the Multiply Handicapped
A. Committee is to appoint an evaluation task force
2. Evaluation criteria composed by task force with input from:



- A. Administrators
- B. Parents
- C. Teachers
- D. Other professionals
- E. Public and private agency representatives
- F. Politicians
- G. State specialists
- 3. Assessment team to be appointed by task force
- 4. Accreditation team to be appointed by task force and given authority from Governor's Advisory Committee to:
 - A. Make recommendations for additional funding
 - B. Compile a list of accredited facilities

Strategy 1.3

Establish appropriate funding support

Tactic 1.3.1

- Obtain funding for birth-to-death age group
 - A. Title VI EHA funds
 - B. Title III ESEA funds
 - C. Developmental Disabilities funds
 - D. Establish programs for birth-to-five-year-old age group and then petition for funds
 - a. demonstrate cost-effectiveness basis
 - E. Search for additional funding
 - a. major medical insurance
 - b. grants, foundations, etc., from agencies, clubs, churches, etc.
 - c. consultant expertise
 - d. local school districts (individually, or through cooperative efforts)
 - e. fund-raising projects
 - f. gifts

Strategy 1.4

Establish communication lines for information dissemination concerning program options

Strategy 1.5

Identify constraints in following areas:

- A. Manpower
- B. Curriculum
- C. Supportive services
- D. Materials
- E. Facilities
- F. Bureaucratic red tape
- G. Inadequate or inappropriate training of teachers
- H. Funding
- I. Attitudes

Strategy 1.6

Incorporate new delivery patterns within existing delivery facilities

Implementation:

- 1. Existing programs to be evaluated by assessment teams upon invitation
 - A. New programs implemented on basis of this evaluation
- 2. Administrators and teachers to implement new programs

GOAL 2.0	CREATE NEW DELIVERY SYSTEMS, APPROPRIATE TO THE NEEDS OF SEVERELY HANDICAPPED CHILDREN
<u>Strategy 2.1</u>	Define or identify new service alternatives
Tactic 2.1.1	Define alternatives for the homebound <ul style="list-style-type: none"> A. Visiting teacher (with support personnel) B. Parent or support personnel training packages C. Telecommunications D. Mobile mini-units
2.1.2	Parent in-service training in demonstration units <ul style="list-style-type: none"> A. Demonstration clinic B. Video-taping C. Foster and residential settings
2.1.3	Contracted services <ul style="list-style-type: none"> A. Professional foster parents B. Group homes (residential halfway houses) C. Individual contracting within community
2.1.4	On-the-job training
Implementation:	Identification of new service alternatives completed by SEA staff
<u>Strategy 2.2</u>	Write descriptions of the above programs to facilitate information dissemination (include bibliography of sources)
Implementation:	Descriptions of new program options will be written by SEA staff
<u>Strategy 2.3</u>	Implement program options according to: <ul style="list-style-type: none"> A. Client needs B. Geographical constraints C. Multi-agency resources
Implementation:	By local school districts, RRCs, colleges and universities, cooperative service agencies
<u>Strategy 2.4</u>	Assess client needs
Implementation:	Assessment of client needs by team in conjunction with serving agencies and parents; additional intensive staffing on request of administrators, staff or parents
Evaluation:	(above goals, strategies and tactics) <ol style="list-style-type: none"> 1. Have objectives been met? 2. Publish a list of criteria for evaluation of existing programs 3. Publish a comprehensive list of new programs and program descriptions as they are developed and implemented 4. Evaluation of specific objectives by task force or appropriate group for each objective

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GOAL 3.0 TO DETERMINE THE BEST PRACTICES IN MANPOWER UTILIZATION AND TRAINING FOR ALL SEVERELY MULTIPLY HANDICAPPED PROGRAMS

Strategy 3.1 To recruit trained educators for the severely, multiply handicapped

Tactic 3.1.1 To develop an adequate method of communicating needs

- A. Notices in national journals
- B. Opportunities at national conventions
- C. Contact universities and colleges
- D. Talk with peers—word of mouth by those who hire or their representatives
- E. Notify related organizations

3.1.2 Provide increased and attractive salary

- A. Educate the legislators (lobby)
- B. Equitable salary and career ladders
- C. Contract for services
- D. Change administration policy on salary and contracts
- E. Arbitration by teachers and others

3.1.3 Incentive pay for rural and remote areas (consultative time allowances)

3.1.4 Extend professional development of rural/urban agencies that is of value to be affiliated with

Resources: Comprehensive manpower recruitment, opportunities for more education by educators of severely, multiply handicapped

Implementation: Local education association, intermediate education association, institutions, community agencies—public and private

Evaluation:

1. Document personnel hired showing data by: level, agency, yearly total, attrition rate, where trained, certification and experience
2. Interagency comparison
3. Are objectives fulfilled
4. Are teachers still there
5. Analyze data on information, communication efforts, returns, etc.

Strategy 3.2 To retrain on-staff educators and recruit and train parents, paraprofessionals and volunteers

Tactic 3.2.1 Workshops and institutes

- A. On-site (closed circuit TV, video taping exchange)
- B. At other agencies: RRCs, ALRCs, State LRCs, universities, parent groups (provide scholarships for training) and institutions and agencies for the severely, multiply handicapped



3.2.2	RRC training capability
3.2.3	Developmental Disabilities Technical Assistance System at Chapel Hill, North Carolina—access through the Division of Developmental Disabilities
Resources:	Universities and colleges, UAFs, institutions, RRCs, SEA institutes financed with DDD monies, LEA in-services, parent group training sites and volunteer agencies
Implementation:	Other teachers, paraprofessionals, consultants, universities, agency sponsored in-service training, LEAs, private agencies by contract, and federal support services (RRCs)
Evaluation:	Survey of how many teachers retrained and assess quality of the product by monitoring student growth based data
<u>Strategy 3.3</u>	To obtain training resources from existing institutions, agencies, professionals, etc.
Tactic 3.3.1	Determine who, how and what: i.e., sources of funding for training—BEH, SEA, foundations, community agencies, parent groups, volunteer agencies, religious organizations
3.3.2	Writing grants for projects with training components
3.3.3	Communicate need for new and additional training
3.3.4	Influence educational agencies to develop training for severely, multiply handicapped
3.3.5	Contract with private or public agencies to develop and provide training
Resources:	RRCs, regional HEW offices, state LRCs, state DDD programs, volunteer groups for seed money, volunteer groups for training sites, universities, colleges, etc.
Implementation:	Other teachers, paraprofessionals, consultants, universities, agency sponsored in-service training, LEAs, contract with private agencies and federal support services (RRCs)
Evaluation:	<ol style="list-style-type: none"> 1. Document funding locations 2. Program effect of funding source information and utilization <ol style="list-style-type: none"> A. Who needs information B. Amount of funding C. Innovative changes

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Strategy 3.4 To mount a need assessment of manpower requirements for education for the severely multiply handicapped

Tactic 3.4.1 Determine variables to assess

3.4.2 Develop a search strategy

3.4.3 Obtain funds

3.4.4 Gather data

3.4.5 Analyze results

3.4.6 Gestalt needs

3.4.7 Determine priorities

Resources: LEAs, universities, university students, DDD agencies, comprehensive health planning councils, state education research and planning councils, Head Start and other Title programs

Implementation: RRCs, university students, SEAs, DDD agencies, comprehensive health planning councils and university assistants

Evaluation: 1. Did you get it?
2. Was data relevant and needed?

GOAL 4.0 TO INFLUENCE POSITIVE CHANGE IN POLICY AT ALL LEVELS FOR SEVERELY MULTIPLY HANDICAPPED TO IMPLEMENT APPROPRIATE PROGRAMS

Strategy 4.1 Find out what policy exists at all levels

Tactic 4.1.1 Get report of non-written guidelines

Tools: A survey composed of a questionnaire and/or interview of 25 selected citizens, school administrators and 10 selected members of the instructional staff to determine positiveness, acceptance and commitment as defined in questionnaire toward the severely multiply handicapped to be sent out

Forces: School board association, parent groups, professional groups

Evaluation: Return of 75% of questionnaires

Tactic 4.1.2 Get written rules from all levels

Tools: A survey sent to school boards and state board of education

Forces: School board associations and state board of education, professional and parent groups, universities



Evaluation:	100% of obtainable, available written policy statements will be acquired.
<u>Strategy 4.2</u>	Find out resources
Tactic 4.2.1	Identify agencies providing services to severely, multiply handicapped
4.2.2	Compile a registry of human resources
Tools:	A. Contact state board of education for list of agencies B. Obtain published directories, e.g., Closer Look (BEH), Directory of Services for the Handicapped C. Contact parent groups D. Contact related professions
Forces:	(to carry out the program) Professional and parent organizations: CEC, ACLD, ARC, AAMD, NASDSE, BEH, UCP, DDD agencies
Evaluation:	A. At least 15 agencies providing services will be contracted B. At least 15 specialists in areas of service to severely, multiply handicapped will be contracted
<u>Strategy 4.3</u>	Identification of needs
Tactic 4.3.1	Served and non-served severely, handicapped will be identified
4.3.2	Facilities will be assessed
4.3.3	Manpower will be registered
Tools:	A. Get available data B. Saturation of the media announcing the search for all severely, multiply handicapped C. Questionnaire sent home with children to determine the existence of all severely, multiply handicapped D. Obtain school data
Forces:	(to carry out the program) State agencies, federal agencies, local, i.e., Department of Mental Health, parent groups
Evaluation:	A. At least 15 agencies providing services will be contacted to determine the number of severely, multiply handicapped actually served. Compare national expectancy with actual served and identify at least 100% more which are presently non-served B. List of existing facilities C. List of available personnel

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Strategy 4.4

To design proposal to change attitudes

Tactic 4.4.1

Assign responsibility

4.4.2

Use consultation for analysis of data

4.4.3

Funding

4.4.4

Write out plan

Tools:

A person available to design a model for the proposal by reviewing existing models and consulting experts. A second tool is funds.

Evaluation:

Acceptance of written proposal

Strategy 4.5

Through results of the identification of resources and the needs survey, apply pressure on administrators, school boards, community groups and parents

Tools:

- A. People, interviews, discussions, presentations
- B. Press releases
- C. Utilization of community groups
- D. Legislation—lobbying
- E. Litigation

Forces:

(to carry out the program)
School board association, professional and parent groups, state agencies, federal agencies, local agencies, i.e., Dept. of Mental Health, and universities

Evaluation:

Implementation of proposal

Project

Evaluation:

All severely, multiply handicapped being served



4. WHAT IS RELEVANT EDUCATION?

Resource Person: Louis Brown, Ph.D.

Dr. Brown is Associate Professor, Department of Behavioral Disabilities, at the University of Wisconsin.

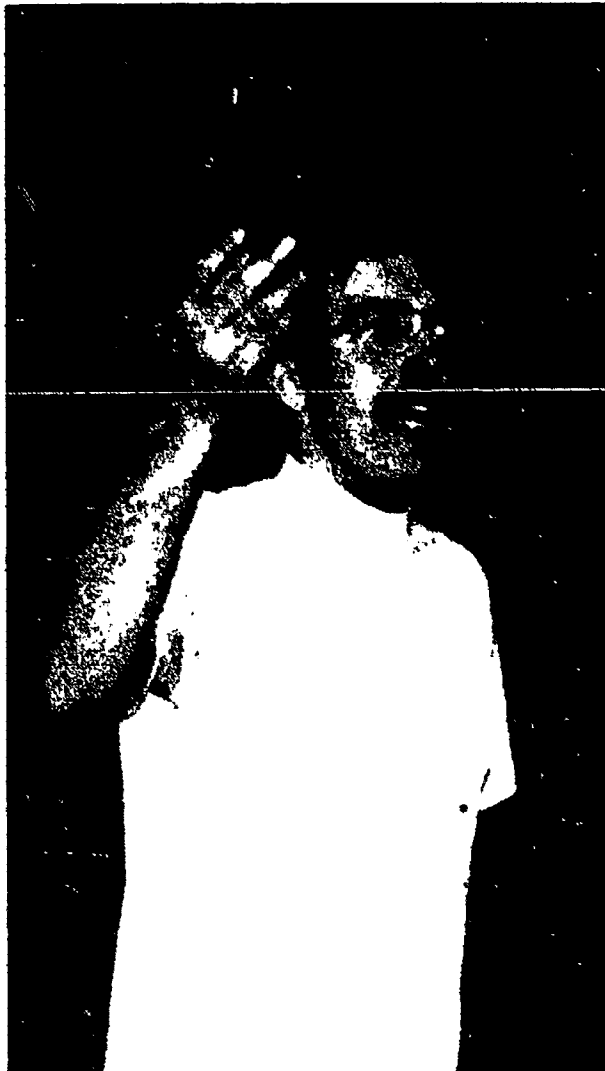
His thematic statement is located in Appendix A.



GOAL 1.0 TO IMPROVE TEACHER TRAINING

PRESERVICE

- | | |
|---------------------|---|
| <u>Strategy 1.1</u> | Coordinate between public school, university and state department |
| Tactic 1.1.1 | Instigate dialogue |
| 1.1.2 | Identify a prime-mover |
| 1.1.3 | RRC to act as coordinator |
| 1.1.4 | Invite university professors to visit public schools |
| 1.1.5 | Articulate what is needed in a teacher |
| 1.1.6 | Develop community advisory committee composed of special education directors, special education teachers, special education students and parent representatives |
| 1.1.7 | Responsibility of community advisory committee:
A. Survey university feedback from students
B. Review university program
C. Survey employer feedback
D. Develop needs assessments
E. Research California's Ryan Act
F. Identify constraints on the university |
| 1.1.8 | University to include representatives from the school district |
| <u>Strategy 1.2</u> | Introduce extensive practicum |
| Tactic 1.2.1 | Identify key locations |
| 1.2.2 | Identify certified teachers and schools |
| 1.2.3 | Expose students to institutional and classroom situations and provide feedback and evaluation on student performance. Wide-range exposure for all students. |
| 1.2.4 | Develop live-in situation for students in residential settings |



1.2.5	Identify legal constraints on practicum requirements
1.2.6	Schedule classes to allow the students to be in the public schools during the day
1.2.7	Recruit students to become active participants in the classroom so the student becomes an indispensable agent in the classroom
1.2.8	Use the student as liaison between the university and the public school on what needs to be taught
1.2.9	Procure Title VI money by writing a proposal that is marketable on a state-wide basis
1.2.10	Look into the possibility of obtaining local money from vocational education funds
1.2.11	Determine model program for demonstration funds
1.2.12	Teachers and students tour workshop areas during the summer and develop task analyses
<u>Strategy 1.3</u>	Joint appointments between LEA and university
IN-SERVICE	
<u>Strategy 1.4</u>	Demonstration centers
Tactic 1.4.1	Select key location for demonstration center
1.4.2	One center, containing entire package of experience and personnel in one key location
1.4.3	Obtain qualified and professional staff
1.4.4	Utilize manpower pool for programming (BEH)
1.4.5	Procure demonstration funds via curriculum manual development for dissemination
1.4.6	Pick children on basis of real need
1.4.7	Use training staff and university in a cooperative effort to insure success of demonstration center
<u>Strategy 1.5</u>	Floating inobile in-service training (IST) facilities-demonstrations
Tactic 1.5.1	Floating library facilities
1.5.2	Set up busmobile-type itinerant schedule
1.5.3	Bring outside classroom groups (with their teacher) into demonstration center

- 1.5.4 Utilize video-tape cassettes which show teachers using material with children
 - A. Differentiate (various procedures with individual children)
- 1.5.5 Outline fundamental learning sequences
- 1.5.6 Vertical-horizontal program (teaching and verification)
- 1.5.7 Preschool demonstration of facilities to take place in the summer before the beginning of the school year.
- 1.5.8 Reincorporate the "poor" teacher with demonstration model

Strategy 1.6 More practical methods courses

GOAL 2.0 TO IMPROVE AND DEVELOP INSTRUCTIONAL CURRICULUM

Strategy 2.1 Review literature and disseminate information

Tactic 2.1.1 Sell idea of information system to school districts in relation to regular education classes

2.1.2 Send it out to teachers in sample form and make them request it because they found it useful

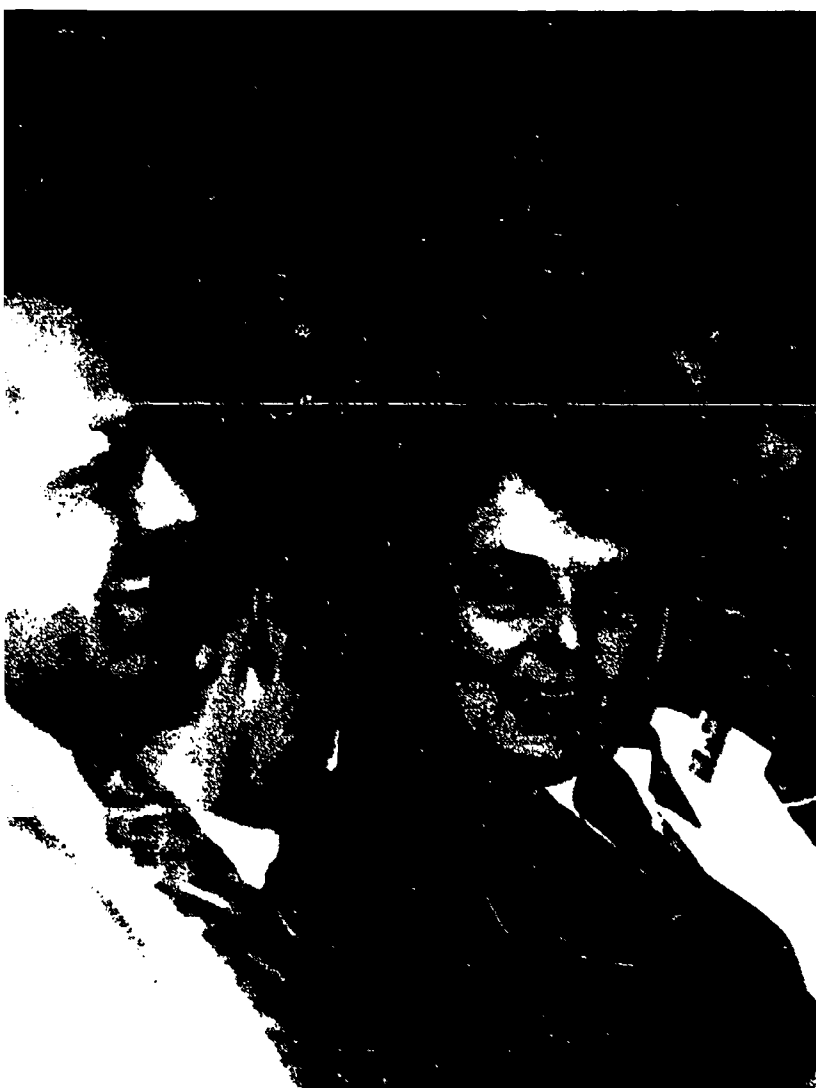
2.1.3 Delineate a manpower pool and get on the mailing list

- Forces:
- (to carry out program)
 - 1. University
 - 2. State department
 - 3. Teachers assigned in each district
 - 4. Area Learning Resource Centers
 - 5. Regional Resource Centers--establish a system for use throughout the country
 - 6. Teachers from each school assigned to the superintendent who has the information
 - 7. Someone (teacher or nonteacher) review, send information out through supportive personnel (resource teacher, etc.)
 - 8. Local CEC chapters

Strategy 2.2 Develop new procedures for working with severely, multiply handicapped

Tactic 2.2.1 Utilization of interdisciplinary coordination: doctors, dentists, occupational therapists, physical therapists, public health nurses, welfare workers, speech therapists, audiologists

- A. Involve professionals
 - 1. Invite them to visit school
 - 2. Get on their advisory boards
 - 3. Invite university students in different



- professions (i.e., medical students to intern in school district)
 - B. Demonstrations given to teachers by specialists in other areas so teachers can carry on if specialists not available
 - C. Money—buy services of doctor, dentist, etc.
 - D. Attend other specialists' conventions
 - 1. Tape proceedings for dissemination of information
 - 2. Lobby; have well conceived plan for requesting help
 - 3. Attend auxiliary meetings (get wives of specialists interested)
 - E. Check on existing agencies (i.e., Crippled Children's Hospital)
 - 2.2.2 Demonstrations
 - A. Video tapes (video libraries)
 - B. Slides and tapes
 - 2.2.3 In-service training during school
 - A. Substitute teachers hired to release teachers for in-service training
 - B. Free Friday afternoons (or staggered)
 - C. Days of professional leave made available
- Strategy 2.3** **Establish more effective utilization of existing mechanisms for sharing new ideas**
 - Tactic 2.3.1 Literature review
 - 2.3.2 Professional organizations such as CEC utilized
 - 2.3.3 Increased sharing of ideas informally among teachers
 - 2.3.4 Mailing lists
- GOAL 3.0 TO DEVELOP STATE STANDARDS TO REFLECT NEEDS**
 - Strategy 3.1** **Identify competencies**
 - Tactic 3.1.1 Organize a task force composed of state, university and local personnel
 - 3.1.2 Regional organization (RRC or ALRC) to disseminate information, national materials, programs, workshops
 - Strategy 3.2** **Changes should be made in certification (tie certification to competencies and three certification levels)**
 - Tactic 3.2.1 Offer provisional certification and alternate licenses (paraprofessional) for those already in the field
 - 3.2.2 Ongoing, periodic review of certification to see if competencies relate to known required

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- 3.2.3 "Emphasis" added to full certification
- 3.2.4 Certification task force reviews practicum experience
- 3.2.5 Change course requirements to match public school requirements (needs)
- Strategy 3.3 Legislate for ratio
- Tactic 3.3.1 Data collection of "real" classroom needs to present to decision makers to show what ratios are adequate
- 3.3.2 Disseminate knowledge on valuable volunteer service programs in region from RRC to ALRC



5. PARENT EDUCATION AND THEIR ROLE

Resource Person: Philip Roos, Ph.D.

Dr. Roos is Executive Director, National Association for Retarded Citizens, Arlington, Texas.

His thematic statement is located in Appendix A.

Recorders: Debbie DeVries, Jan Loveless



GOAL 1.0 TO REACH CONSENSUS BETWEEN PARENTS AND PROFESSIONALS IN DEFINING CLEAR OBJECTIVES

Strategy 1.1 Identify and prioritize perceptions of needs seen by parents and professionals

Tactic 1.1.1 Survey of professionals as well as of parents

1.1.2 Sample representatives from groups

Tools: Check list of needs

Strategy 1.2 Cooperative exchange of information and feelings about needs and their priorities for handicapped children

Tactic 1.2.1 Small group meetings in which professionals reach consensus

1.2.2 Small group meetings in which parents reach consensus

1.2.3 Regularly scheduled, open discussion meetings to discuss concerns and make reevaluations

1.2.4 Local problem-solving meetings (group and individuals) in which all concerns are honored and received

Tools: Ongoing written needs assessment by both involved groups

Forces: 1. RRC representative contacting and leading all governmental and private organizations concerned with services for the severely, multiply handicapped; i.e., state board of education, organized consumer representatives (ARC, UCP, ACLD), Health Department, Vocational Rehabilitation (adult services)

Evaluation Strategies:

1. Compile statistics on meetings: i.e., number of meetings, number in attendance, etc.
2. Transcription of tape recordings of meetings and interaction analysis

-
- 3. Attitude survey
 - 4. Parents' and professionals' concerns are expressed in a combined list
- Evaluation Needs:
- 1. Interaction analysis scales, e.g., Flanders, Hill
 - 2. Questionnaires, e.g., "Were you able to express yourself?" "Did people listen to your concerns?"

GOAL 2.0 TO PROVIDE AND COORDINATE COMMUNITY BASED, PARENT-RELATED SERVICE PROGRAMS

- Strategy 2.1 Develop and establish an interagency committee serving the handicapped
- Tactic 2.1.1 Determine needs of the handicapped
- 2.1.2 Determine available services and define responsibilities
- 2.1.3 Develop meaningful and achievable programs
- 2.1.4 Make interagency participation part of the job description
- Strategy 2.2 Develop and establish an advisory council to the interagency group consisting of parents (consumers)
- Tactic 2.2.1 Interagency recruitment of parent participants on advisory council
- 2.2.2 Advisory council meetings would be open to consumers of agency services
- 2.2.3 A rotating member of the advisory council would attend meetings of the interagency committee to share their identified needs
- 2.2.4 Technical assistance to advisory council would be provided by rotating members of the interagency committee
- Strategy 2.3 Plan and develop a service coordinating agency
- Tactic 2.3.1 Establish an independent task force
- 2.3.2 Define the role of the coordinating agency
- Tools:
- 1. Research existing models for service coordination
 - 2. Funding
 - 3. Directories
 - 4. Service Clubs
 - 5. Media
 - 6. Speak-ups
 - 7. Survey - needs assessment
 - 8. Advisory council to design role of and appoint coordinating agency

- Forces:**
1. Service organizations
 2. State agencies
 3. Legislative influences
 4. University related facility
 5. Special education personnel
 6. Health services
 7. Consumers
 8. Media

- Evaluation Strategies:**
1. Compare data of served and unserved children (initial - 1 year)
 2. Compare data of inappropriately served children (initial - 1 year)
 3. Are parent/child-related services established? (initial-1 year)

- Evaluation Needs:**
1. Advisory council will evaluate parent-related services
 2. State, local surveys (e.g., ACCESS)
 3. Oregon model for service coordinator

GOAL 3.0 TO PROVIDE FOR AND INCREASE PARENTAL UNDERSTANDING, KNOWLEDGE AND SKILLS

Strategy 3.1 Develop a communication coordination center

Tactic 3.1.1 Secure funds

- Tools:**
1. Establish a ways and means committee to raise money
 2. Write a proposal of goals of the center

Tactic 3.1.2 Develop a facility, staff and resources

- Tools:**
1. Secure a building and equipment
 2. Obtain a list of local and state resources and secure commitments to cooperate and share

Strategy 3.2 Develop systematic parental involvement

Tactic 3.2.1 The center will have information available

- Tools:**
1. Brochures, newspapers, radio and television
 2. Talks: speakers would be parents, teachers, psychologists, legislators, lawyers and doctors

Tactic 3.2.2 To outreach into the homes

- Tools:**
1. In-service training by parents, teachers
 2. Brochures, letters
 3. Service organizations
 4. Recruit parent volunteers into special classes--(paraprofessions, coordinators)

- Forces:**
- Those in existence:
1. Private foundations, service agencies
 2. Civic: Jaycees, Lions, Rotary, etc.
 3. Local media

4. Students
 5. Professional: medical, legal, educational, therapeutic
 6. Parents
- Need to create:
1. Temporary coordinator to establish agency board consisting of representatives from established forces
 - a. Coordinator and executive director appointed by agency board
 - b. Fund raising committee

Evaluation Strategies:

- (Formative and Summative)
1. Criterion-referenced model based on performance objectives for parents and children
 2. Surveys, i.e., questionnaires and interviews
 3. Standardized tests

Evaluation Needs:

1. Develop a questionnaire to evaluate quality and knowledge of current services to parents; questionnaire to be sent out before and at end of the year
2. Criterion-referenced instruments for parents and students
3. Standardized tests
4. Interview with parents on random samples

GOAL 4.0 TO ARTICULATE AND ENABLE PARENT ROLES IN SERVICE DELIVERY

Strategy 4.1

Early childhood training, using the family in primary intervention

Tactic 4.1.1

Professional team goes to the home, develops and carries out infant stimulation program with the family

Tools:

1. Packaged materials
2. Diagnostic equipment and expertise
3. Skills for observing child
4. Skills in interpreting findings to the family
5. Skills in designing home training programs

Tactic 4.1.2

In-service workshops for parents

Strategy 4.2

Continuous training utilizing family participation

Tactic 4.2.1

In-service workshops for parents

4.2.2

Ongoing evaluation system

Tools:

Professional team goes to the home, develops and carries out infant stimulation program with the family

Strategy 4.3

Parent organization and participation

Tactic 4.3.1

Instigate parent group and parent-professional group

	Tools:	1. Constitutions for parent groups
Tactic 4.3.2		Student-related staff policy of open invitation to observe and participate
	Tools:	1. Printed staff policies related to program personnel 2. Publicity: television, radio, newspapers
<u>Strategy 4.4</u>		Open communication between parents and professionals
Tactic 4.4.1		Active resource pool of specialists and resources lawyers, legislators, etc.
	Tools:	List of names of specialists
Tactic 4.4.2		Instructional materials
	Tools:	Pre-packaged materials and programs and an open appointment book
Tactic 4.4.3		Practicing receptivity and honesty between parents and professionals
	Tools:	"Help-line": available telephone services
	Forces:	1. Interdisciplinary team: nurse, family doctor, therapists, psychologists, medical specialist, social worker 2. Home school program coordinator 3. Families 4. Teachers 5. Workshop directors 6. Public relations media 7. PTA or ARC team groups and other parent groups
	<u>Evaluation Strategies:</u>	1. Observation 2. Measure of parent effectiveness with child in all areas of skills: social, educational, etc. 3. Measure effectiveness of groups' accomplishments 4. Measure of parent and professional growth
	Evaluation Needs:	1. Parent conferences 2. Tests: vocational evaluation, (Vineland), PACE circular, (Kephart) 3. Pre- and post-questionnaire for program 4. Teacher inventories 5. Family observations and charting 6. Quantity and quality of parent involvement
GOAL 5.0		TO INCREASE PROFESSIONAL UNDERSTANDING, KNOWLEDGE AND SKILLS
<u>Strategy 5.1</u>		Design and implement state-wide educational programs to increase basic knowledge of severely

	handicapped conditions on the part of all professionals who deal with parents
Tactic 5.1.1	Determine the level of knowledge of professionals working with parents by survey inventories, information tests
Tools:	1. Survey inventory 2. Information tests
Tactic 5.1.2	Provide training for existing professionals working with parents
Tools:	1. In-service training at regular professional staff meetings
Tactic 5.1.3	Develop or improve preservice training programs for professionals working with parents
Tools:	1. Competency-based degree program with practicum experience 2. Curriculum changes in training programs
Tactic 5.1.4	Develop professional standards for those working with parents
Tools:	Coalition of parents and professionals to establish professional standards
<u>Strategy 5.2</u>	Design and implement a state-wide program to increase specific skills of parent trainers
Tactic 5.2.1	Identify skills needed by parent trainers
Tools:	Literature search
Tactic 5.2.2	Develop a program and staff to teach those skills
Tools:	Competency-based degree program with practicum experience
<u>Strategy 5.3</u>	Design and implement state-wide programs to increase acceptance attitudes of professionals toward parents and their severely handicapped children
Tactic 5.3.1	Develop awareness of attitudes among professionals and assess them
Tools:	1. Gestalt group techniques 2. Role-playing
Tactic 5.3.2	Include experiential content in professional training
Tools:	1. Regular practicum experience 2. Role-playing
Forces:	1. Organized parent groups 2. Knowledgeable professionals retained by



- state and local agencies
- 3. Qualified trainers to work in college or university setting
- 4. An advisory committee representing parent and professional organizations
- 5. Professional lobbyist retained by parent groups to effect change in preservice training institutions
- 6. Research specialist
- 7. Management specialist, educational programmer, technical competency specialist, information materials specialist, evaluation specialist
- 8. Informed parent professional groups to communicate with professionals
- 9. Professionals skilled in attitude change techniques, retained by parent groups to work with professionals

Evaluation
Strategies:

- 1. Measure change of behavior or professionals toward the target population--parents and severely, multiply handicapped children
- 2. Assess parent knowledge, understanding, and skills
- 3. Evaluate change in attitudes of professionals
- 4. Evaluate change in professional knowledge

Evaluation
Needs:

- 1. Parent survey
- 2. Observation of professional behavior
- 3. See needs for evaluation strategy no. 3
- 4. Parent participation on training and other programs
- 5. Professional involvement in community organizations and activities
- 6. Survey of professional attitudes
- 7. Test of knowledge and skills (criterion-referenced)
- 8. Evaluation of change in monies expended for services to severely, multiply handicapped



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TIMELINES, BY STATE AND NATIONAL WORKSHOP GROUPS

Participants in each of the four state workshops had the enormous assignment of trying to concretely apply the wisdom of the conference to the needs of their own state. The allotted time for this task was a meager 1 hour and 15 minutes. Yet this was a most necessary effort, even with such constraints. The national workshop (38 participants representing 14 states and the District of Columbia) sought to apply the decisions of the conference primarily to the federal structures. Their work took the shape of recommendations and goals, instead of a timeline.

All five workshops tried to limit their concern to a one-year period, with the states developing one-year timelines by quarters. It is important to underscore that even though more time was needed to fully complete this assignment, many of the recommendations are well articulated and valid, and should be taken seriously as starting points for service. As you refine the work here, remember that the thinking that led to these pages was concentrated, collective and intense.

The information in this section appears in the words of those who participated. The entries were necessarily cryptic. For a complete understanding of the tactics or strategies listed, refer back to the information generated in the specific workshop. The goals, strategies and tactics from the workshop - plus the timeline - chart the steps the participants would like to take in their own states. Perhaps some of these first steps in improving services to the severely, multiply handicapped have, by now, been taken.



TIMELINE — IDAHO

SPRING, 1974 (March-May)	SUMMER, 1974 (June-August)
<p>1. SYSTEMATIC DELIVERY SYSTEM</p> <ul style="list-style-type: none"> ●State Department of Education will appoint a task force and/or advisory board composed of key people of state and local agencies and groups serving severely multiply handicapped children to develop or clarify Idaho's philosophy regarding service to severely multiply handicapped children. This task force/advisory board will also review rules and regulations affecting this population and current information regarding the needs of Idaho's severely multiply handicapped children 	<ul style="list-style-type: none"> ●The task force/advisory board will disseminate information regarding this conference and information regarding task force activities
<p>2. IDENTIFICATION OF CONSTRAINTS</p> <ul style="list-style-type: none"> ●The governor should require each agency to provide a written document (in directory form) that would list information on what is available in federal, state, local funds; who is contact person, what projects can be included; what priorities exist. This would begin immediately and be an ongoing service ●Workshops to train state professionals in grant writing--by regions or on a state basis beginning in April/May to be helpful before FY75 begins. ●Have curriculum in colleges to assist special education teachers in multiply handicapped to use common terminology in their work 	<ul style="list-style-type: none"> ●Program reports and cost allocation plans should be developed for each agency or program relating to severely multiply handicapped starting in July ●Develop statewide coalition (regions, grass roots) to influence bureaucracy <ul style="list-style-type: none"> July 1—Identify groups August 31—Form ad hoc committee to assemble leaders who can have influence
	<p style="text-align: center;">➤</p> <ul style="list-style-type: none"> ●Focus on public awareness of needs and rights of the severely multiply handicapped ●Have in-service training for professionals in four locations of the state to establish common priorities ●Have on-going meetings of committees of the legislature
<p>3. OPTIONS FOR THE UNSERVED CHILD</p> <ul style="list-style-type: none"> ●Compile index of existing services <ul style="list-style-type: none"> •have SEA publish index ●Establish a Governor's Advisory 	<ul style="list-style-type: none"> ●Evaluation criteria composed by task force with input from: administrators, parents, teachers, other

FALL, 1974 (September-November)	WINTER, 1974-75 (December-February)
<ul style="list-style-type: none"> ● Conduct a census within local school districts, agencies and institutions serving severely multiply handicapped children of served and unserved target population 	<ul style="list-style-type: none"> ● Advisory board/task force will act as catalyst to search out available funds to initiate at least one pilot program in Idaho to improve existing services to severely multiply handicapped children and at least one pilot program to initiate services to severely, multiply handicapped children previously unserved. Provide technical assistance to this project and disseminate effectiveness of pilot programs ● The advisory board/task force will investigate the feasibility of a follow-up workshop on severely handicapped children
<p>→ (See Note)</p>	
<p>→</p> <p>→</p>	<p>→</p>
<ul style="list-style-type: none"> ● Assessment team to be appointed by task force ● To retrain on-staff educators and 	<p>→</p>

SPRING, 1974 (March-May)	SUMMER, 1974 (June-August)
<p>Committee for the Multiply Handicapped</p> <ul style="list-style-type: none"> ●Mount a need assessment of manpower requirements for severely multiply handicapped ●Find out what policy exists at all levels <ul style="list-style-type: none"> •get report of non-written guidelines •get written rules from all levels ●Identification of needs <ul style="list-style-type: none"> •identify served and non-served severely multiply handicapped population •identify facilities •identify manpower 	<p>professionals, public and private agency representatives, politicians, and state specialists</p> <ul style="list-style-type: none"> ●Obtain training resources from existing institutions, agencies, professionals ●Design proposal to change attitudes <ul style="list-style-type: none"> •assign responsibility •use consultation for analysis of data •funding •write out plan
<p>4. WHAT IS RELEVANT EDUCATION</p> <ul style="list-style-type: none"> ●Review possible locations (existing) for demonstration center ●Disseminate information through existing conference ●Pool existing data relative to severely handicapped/multiply handicapped in state ●Have state department survey existing national programs ●Have state department conduct in-service teacher training <ul style="list-style-type: none"> •spring workshop in Idaho •definition of multiply handicapped/severely handicapped (BEH definition) •programs for severely handicapped/multiply handicapped development •training •representatives: teachers--regular and special education, medical, universities, LRCs, RRCs, public school administrators, parent associations--ARC, PTA, CEC, legislators, psychologists, social workers, speech therapists, Department of Environmental and Community Services. 	<ul style="list-style-type: none"> ●Compose curriculum guides from surveys for severely multiply handicapped ●Increase mandatory training requirements for certification to include extensive practicum <ul style="list-style-type: none"> •making it mandatory that preservice students be given opportunity and obligation to develop competencies with severely handicapped children <p style="text-align: center;">➤</p>

FALL, 1974 (September-November)	WINTER, 1974-75 (December-February)
<p>recruit and train parents, paraprofessionals and volunteers</p> <p>➔</p>	<ul style="list-style-type: none"> ● Accrediting team to be appointed by task force and given authority from Governor's Advisory Committee to make recommendations for additional funding and to compile a list of accredited facilities ● Recruit trained educators for the severely multiply handicapped ● Having results of the needs assessment apply pressure on administrators, school boards, community groups and parents
<ul style="list-style-type: none"> ● Begin establishment of demonstration center ● State coordination for severely handicapped/multiply handicapped classes and curriculum so as to preserve a program which adequately fulfills the needs of state (one good program--not three bad programs) ● Awareness campaign should be conducted ● Survey existing legislation and draw up proposals for new legislation ● Determine specifications and competencies in severely handicapped/multiply handicapped programs <ul style="list-style-type: none"> • survey state needs: RRCs, SEAs, LEAs, state associate centers • survey national existing programs LRCs, RRCs, DDDs, state associate centers • delineate training and instructional programs <ul style="list-style-type: none"> competencies objectives curriculum: academic, social and vocational methods: custodial versus behavioral measurement: accountability ● Designate sources for specification of competencies: parents, universities, public schools, teachers, agencies, administrators, state department, institutions, vocational rehabilitation, RRCs, LRCs, DDDs 	<ul style="list-style-type: none"> ● Demonstration center is operating ● Conduct evaluation <ul style="list-style-type: none"> state coordinator for all severely handicapped/multiply handicapped is responsible for referrals, continuity of programs, assured services for all infant to schoolage program (Head Start) regional demonstration centers in-service workshops: joint demonstration programs ● Skill orientation practicum (specific training program for severely handicapped/multiply handicapped) ● Continuing adult education--adult welfare, sheltered workshops, rights and protection (Department of Environmental and Community Services, Welfare and Vocational Rehabilitation) ● Funding (Designate appropriate ratios, 1/4 or 1/8 with/without aide, or fund demonstration units only) ● Certification standards: define target population, ratios, practicum, academic, competency based criteria ● New endorsement for severely handicapped/multiply handicapped <ul style="list-style-type: none"> • no mentally retarded endorsement valid for severely handicapped/multiply handicapped programs • interim status to present mentally retarded endorsements (3 years): pretraining and in-service training for all mentally retarded endorsements desiring severely handicapped/multiply handicapped endorsement

SPRING, 1974 (March-May)	SUMMER, 1974 (June-August)
<p data-bbox="532 482 1095 514">5. PARENT EDUCATION—THEIR ROLE</p> <ul style="list-style-type: none"> <li data-bbox="532 547 1005 638">●ARC will identify community based parent organizations which provide services <li data-bbox="532 640 1005 761">●Request DDD council to coordinate meeting of state-level organizations and ask that they make commitment for cooperation 	<ul style="list-style-type: none"> <li data-bbox="1160 547 1661 638">●Have groups redefine their organizations in order to cooperate more fully fully with others <li data-bbox="1160 640 1729 731">●Give guidance to group meetings locally: recommend that the state department of education gives guidance <li data-bbox="1160 734 1729 825">●Utilize all parent and professional groups in the process of reaching consensus on defining clear objectives

FALL, 1974 (September-November)	WINTER, 1974-75 (December-February)
	<ul style="list-style-type: none"> ● Progress report and evaluation

TIMELINE – MONTANA

SPRING, 1974 (March-May)	SUMMER, 1974 (June-August)
<p>1. SYSTEMATIC DELIVERY SYSTEM</p> <ul style="list-style-type: none"> ● Establish attitudes and philosophies ● Identify population ● Identify personnel responsible for implementing overall goal ● Identify existing programs, personnel, facilities, funds, etc. 	<ul style="list-style-type: none"> ● Form task force committee on legislation ● Identify program needs and determine gaps
<p>2. IDENTIFICATION OF CONSTRAINTS</p> <ul style="list-style-type: none"> ● Inservice training ● Set priorities for local areas ● Provide sectional meetings in professional disciplines for severely handicapped ● Identify state-wide communication process ● Evaluation of function of committee 	<ul style="list-style-type: none"> ● Publish and disseminate priorities to defined locale ● Contact local volunteer groups ● In-service special and regular teachers concerning potential limitations of severely handicapped ● Develop accountability evaluation summary ● Composition of group presentation for fair and equal representation in services
<p>3. OPTIONS FOR UNSERVED CHILD</p> <ul style="list-style-type: none"> ● Determine needs & population ● Outline program and goals ● Sell program to the Board ● Obtain indexes of public and private sources of funds and manpower ● Discover related agencies ● Evaluate old programs ● Establish effective lines of communication so that no program overlap exists ● Identify constraints ● Incorporate new patterns into existing systems ● Determine existing written/unwritten policies and rules 	<ul style="list-style-type: none"> ● Identify new services, agencies and facilities available ● Include parents and other interest groups for needs, etc. ● Design general program for funding and acceptance ● Hire professionals ● In-service training of teachers aides, parents, etc. ● Design specific programs - goals and means for evaluation ● Arrange for transportation and housing ● Design and maintain a public relations campaign
<p>4. WHAT IS RELEVANT EDUCATION?</p> <ul style="list-style-type: none"> ● Identify a prime mover to set up community advisory committee (resource Ryan Act-California) (information output) ● Interaction between University and 	<ul style="list-style-type: none"> ● Review for university requirements and certification. Have sophomore teacher experience ● Secure Title VI and Voc. Ed. funds

FALL, 1974 (September-November)	WINTER, 1974-75 (December-February)
<ul style="list-style-type: none"> ●Design program for delivering services ●Specify personnel responsible for implementing specific program 	<ul style="list-style-type: none"> ●Implement program
<ul style="list-style-type: none"> ●Survey current attitudes and needs ●Identify professionals ●Identify resources that may contribute to awareness campaign ●Develop multi-media presentations ●Dissemination of information in medical offices ●Fiscal accountability (initiate) ●Identification of interested groups 	<ul style="list-style-type: none"> ●Establish leadership for conference ●Prepare proposal for deans ●Locate representatives in helping services ●Utilize existing volunteer agencies Organize events to demonstrate severely handicapped ●Identify funding agencies - and grant writing specialists ●Form conference for assembling committee leaders
<ul style="list-style-type: none"> ●Implementation ●Include volunteers and provide for their training ●Continue communication with similar groups/P.R. with population served - "show and tell" parent-teacher conferences; parents day ●Home visits ●Consultants 	<ul style="list-style-type: none"> ●Evaluate progress of program ●Plan for improvements in program ●Accreditation ●Reapply for funds
<ul style="list-style-type: none"> ●Practicums (then workable) <ul style="list-style-type: none"> •locations •maximum exposure to institution and classroom situation ●Live-in situations 	

SPRING, 1974 (March-May)	SUMMER, 1974 (June-August)
<p>public school systems (effective working teams for evaluation purposes)</p> <ul style="list-style-type: none"> ●Develop state standards to reflect needs <ul style="list-style-type: none"> ●Improve and develop instructional curriculum ●Community Advisory Committee (information output) (administration awareness) ●Locate manpower pool and get on mailing list 	<ul style="list-style-type: none"> ●Set up model program for demonstration funds ●Task force to evaluate teacher competency (parents, state, university, teachers and local personnel) ●Set up national standards for competency and certification <ul style="list-style-type: none"> •offer provisional certification and alternate licenses for semi-professionals ●Establish ratio standards ●Cataloging existing professional agencies at national, regional, state, district and city levels
<p>5. PARENT EDUCATION: THEIR ROLE</p> <ul style="list-style-type: none"> ●Develop a survey tool ●Implementation of survey tool in needs assessment ●Parent meetings to coordinate efforts toward consensus ●Joint coordinated meetings between parents and professionals to discuss parent needs ●Solicit firm commitments towards cooperation between parents and professionals in upgrading parent education 	<ul style="list-style-type: none"> ●Determine available services in local areas ●Establish a visible community based point of contact for parents seeking services and information to include local, state, and national levels ●Invite key committed professionals to help establish a means of information dissemination to other professionals ●Initiate involvement of parent and professionals in planning parent education

FALL, 1974 (September-November)	WINTER, 1974-75 (December-February)
<p>in institutions for teacher trainees</p> <ul style="list-style-type: none"> ●Begin developing regional computer center for severely handicapped to be used as teacher resource (by subscription) Task analysis services ●Regional inter-specialist team to consult with teachers, parents, dental, public health nurse, welfare, recreation, doctor (use intern help) ●In-service <ul style="list-style-type: none"> •one free Friday afternoon a month; •plan ways to free teachers for •in-service training 	<ul style="list-style-type: none"> ●State library on teacher techniques from other teachers (begin task analysis services here) ●This will become the demonstration center
<ul style="list-style-type: none"> ●Develop, implement, or improve preservice training programs for professionals working with parents ●Inservice workshops for parents to provide skills in relating to professionals ●To coordinate understanding and develop reciprocal involvement between parents and professionals ●Cooperative planning and programming between parent and professional 	<ul style="list-style-type: none"> ●Evaluation of goals ●Critique of year's plan ●Initiate planning for the coming year

TIMELINE — UTAH

SPRING, 1974 (March-May)	SUMMER, 1974 (June-August)
<p>1. SYSTEMATIC DELIVERY SYSTEM</p> <ul style="list-style-type: none"> ●Promote discussion of issues among special educators, state department officials, school-administrators, parents, and agency personnel ●Articulate and prepare philosophy agreeable to those who will provide and receive service ●LEAs will be responsible for identification of severely multiply handicapped ●Organize publicity: awareness of intention to provide services ●Task force (service providers and consumers) review laws and regulations to determine if they permit state to act in accordance with its philosophy <ul style="list-style-type: none"> •recommend changes •inform parents, secure support ●Identify specific responsibilities of each person involved in services: SEA, LEA, legislators, institutions, parents, etc. 	<ul style="list-style-type: none"> ●Determine total personnel needs ●Identify target: i.e., UEA, media, other agencies ●Identify service patterns ●Describe existing programs ●Describe new programs needed ●List existing facilities ●Locate and establish additional facilities needed ●Determine financial need <ul style="list-style-type: none"> •current financing •projected financial needs
<p>2. IDENTIFICATION OF CONSTRAINTS</p> <ul style="list-style-type: none"> ●Systematic collection and dissemination of available information for funding--to appropriate legislators, state agencies, local governmental units ●Professionals and parents share knowledge and techniques to jointly determine priorities 	<ul style="list-style-type: none"> ●Form coalition of consumers and providers ●Ongoing legislative committee meets regularly with providers of special services ●Appoint more providers to decision-making boards ●Identify interested groups ●Form conference for assembling leaders; develop ad hoc committee ●Adopt curriculum and new views toward severely multiply handicapped that incorporate common terminology ●Clarify existing funding mechanisms ●Increase opportunities for inter-agency cooperation

FALL, 1974 (September-November)	WINTER, 1974-75 (December-February)
<ul style="list-style-type: none"> ●Implement program for the severely multiply handicapped ●Delineate preliminary goals based on needs assessment and present information to parent and professional groups for refinement ●Develop alternative models for systematic delivery system ●Review existing delivery models ●Make recommendations for pilot programs <ul style="list-style-type: none"> •provide technical assistance for implementation of pilot programs ●Lobby for legislation <ul style="list-style-type: none"> •mandate •funds ●Make provisions for other funds 	<ul style="list-style-type: none"> ●Develop means of assessing capabilities of services to meet needs systematically ●Determine if all severely multiply handicapped have been identified <ul style="list-style-type: none"> •census •social services and others ●Determine if individual needs of severely multiply handicapped children are being met <ul style="list-style-type: none"> •criterion measure •periodic evaluation ●Update needs assessment ●Evaluate year's progress
<ul style="list-style-type: none"> ●Establish system for identifying severely multiply handicapped children—in and out of school—not receiving appropriate services ●Provide resource personnel who can advocate for existing programs ●In-service training for inter- and intradisciplinary staff ●Recruit and select in-service training team ●Survey professionals' current attitudes and needs ●Conduct local workshops to develop information and action on <ul style="list-style-type: none"> •knowledge of issues •lobbying •publicity (encourage individuals to write congressmen; get commitment for individuals to work unitedly) ●Include medical profession in campaign for awareness of the handicapped as human beings 	<ul style="list-style-type: none"> ●Conferences to set priorities for local areas concerning severely multiply handicapped ●LEA special education personnel, informed of services for severely, multiply handicapped, will inform others (special and regular education teachers, ancillary personnel) ●Include churches in campaign to increase awareness of handicapped as human being ●Arrange presentations to civic groups to include demonstrations of abilities of severely handicapped children ●Utilize handicapped students as teachers and aides ●Utilize elementary school peers as "special friend" or advocates for severely multiply handicapped children

SPRING, 1974 (March-May)	SUMMER, 1974 (June-August)
<p>3. OPTIONS FOR UNSERVED CHILDREN</p> <ul style="list-style-type: none"> ● Determine what policy exists at all levels ● Identify resources <ul style="list-style-type: none"> • identify agencies providing services to severely multiply handicapped • compile registry of human resources ● Identify needs <ul style="list-style-type: none"> • served and unserved multiply handicapped • facilities • manpower ● Survey 25 selected citizens, 25 school administrators and 10 instructional staff personnel to determine positiveness, acceptance and commitment as defined in questionnaire toward severely handicapped ● Survey school boards and USBE ● Contact USBE for list of agencies ● Obtain published directories ● Contact parent groups ● Contact related professions ● Saturate media ● Questionnaire sent home with school children to determine identification of all children 	<ul style="list-style-type: none"> ● Design proposal to change attitudes <ul style="list-style-type: none"> • assign responsibility • use consultant to analyze data • funding • write plan ● Using results gained from spring activities, apply pressure on administrators, school boards, community groups and parents ● Designate a person to design a model by reviewing existing models, persons
<p>4. WHAT IS RELEVANT EDUCATION?</p> <ul style="list-style-type: none"> ● Follow-up conference; detail strategies by committee comprised of representatives from State Board of Higher Education, USBE, LEAs (Prime mover: MR Specialist, USBE) ● Consumer groups publicize issues ● USBE representative forms a Task Force of USBE, university and public school personnel ● RRC develop national manpower pool with agencies dealing with severely, multiply handicapped on mailing list ● Agencies/State develop computer centers of information on severely multiply handicapped, using federal funds ● Extensive information/literature dissemination in university student teaching programs ● Area and regional resource centers and media center disseminate accumulated information to districts ● Information obtained from ERIC 	<ul style="list-style-type: none"> ● Detailed plan mailed to conference participants on how coordinated relationship will be established in following areas: <ul style="list-style-type: none"> • practicum experience • demonstration center • preservice training • inservice training • advisory committee • minimum list of competencies • all severely multiply handicapped • children should have in education ● Regional information group formed ● Task Force review <ul style="list-style-type: none"> • contact BEH for funding information • contact professional standards project • input from all levels and types of • interested parties (social workers, physical therapists, etc.) ● Task Force designs flexible certification program for paraprofessionals and professionals ● Task Force collects information for

FALL, 1974 (September-November)	WINTER, 1974 (December-February)
<p>➤ (See Note)</p>	<ul style="list-style-type: none"> ●Retrain and train current professionals ●Obtain copies of written policy statements ●Evaluate at least 15 agencies which provide services ●Evaluate services enacted through the year
<ul style="list-style-type: none"> ●Demonstration centers identified and operating ●Practicums for in-service training initiated ●Advisory committee holding hearings on program improvement ●Implement strategies to bring all teachers to minimum competency level ●Task Force finishes design for flexible certification program and definition of appropriate education ●Workshop of concerned personnel to review progress ●List of professional organizations are funneled to USBE and sent out to all LEAs, classes, etc. ●Coordination of interdisciplinary abilities of various specialists (e.g., speech pathologists, physical therapists) and use existing agencies for coordination ●Organize meetings/seminars where teachers share effective ideas 	<ul style="list-style-type: none"> ●Hold accountability conferences <ul style="list-style-type: none"> •progress reports from all programs •implemented during the year •evaluate and develop new strategies •and a new timeline ●Begin implementation of model programs in different parts of the state ●Begin legislation

FALL, 1974 (September-November)	WINTER, 1974 (December-February)
<ul style="list-style-type: none"> ● Disseminate survey on needs and priorities ● Analyze returned data ● Hire coordinator and staff; set up building; contact agencies; plan of action developed for center ● Advisory or policy-making board established by steering committee ● Begin to develop training modules for use in selected programs 	<ul style="list-style-type: none"> ● Begin small group meetings of professionals and consumers to react to and reevaluate check lists ● Implement plan of action for center ● Pre-test attitudes ● Implement training modules <ul style="list-style-type: none"> • experiential content • formal instruction ● Begin to develop a paraprofessional/professional certification for parent training for state (USBE Instructional Support Services Administrator)
<ul style="list-style-type: none"> ● Project Identification update <ul style="list-style-type: none"> • evaluate ability to meet identified needs • fill in gaps, using DDD agencies and advisory council • begin implementation of plan for developmental teams for state • select personnel • purchase equipment • hold parent workshops in target areas 	

TIMELINE — WYOMING

SPRING, 1974 (March-May)	SUMMER, 1974 (June-August)
<p>1. SYSTEMATIC DELIVERY SYSTEM</p> <ul style="list-style-type: none"> ● Promote discussion of the issues among special educators, state department, school administrators, parents and other agencies. ● Prepare philosophy agreeable to those providing and receiving services ● Inquire about children with local welfare and service agencies ● Organize a publicity program that will make people aware of intent to provide service and encourage them to report existence of children needing service ● Task force committee review laws and recommend necessary changes ● Have parents informed of legal issues in order to secure their support ● Identify specific responsibilities of each person involved in providing service <ul style="list-style-type: none"> • state department, school district, legislators, institutions, parents, other agencies, parent and professional organizations, and federal people 	<ul style="list-style-type: none"> ● Delineate primary goals (based on needs assessment) and present to parent and/or professional groups for refinement ● Review existing delivery models ● Recommendations for pilot programs ● Provide technical assistance for implementation of pilot program ● Promote chosen program ● Lobby for enabling legislation <ul style="list-style-type: none"> • mandate • funds ● Provisions for other funds
<p>2. IDENTIFICATION OF CONSTRAINTS</p> <ul style="list-style-type: none"> ● Conduct survey of professionals' current attitudes and needs ● Identify by national, state, local existing resources ● Conduct a workshop to identify technical assistance people in the state or who serve the state ● Department of education plan and conduct a series of workshops with appropriate agencies, administrators teachers, fiscal managers, evaluators, citizens and handicapped persons ● Identify groups interested—order of contact: citizens, ARC; LEAs; CEC, professional groups; SEAs 	<ul style="list-style-type: none"> ● Recruit and select the in-service training team ● Technical assistance people as designated will develop a package of awareness materials (multimedia, literature, demonstration training, etc.) ● Establish a communication process that will insure mutual understanding of the program, the target group, the method of reaching goal ● Develop tools such as program or activities report; for fiscal accountability develop a cost allocation plan, line items ● Form coalition of interested groups, consumers and providers together ● Increase number of providers on decision-making boards

FALL, 1974 (September-November)	WINTER, 1974-75 (December-February)
<ul style="list-style-type: none"> ● Identification of target population <ul style="list-style-type: none"> • LEAs • other agencies • media (electronic and print) ● Identification of existing personnel by discipline <ul style="list-style-type: none"> • survey LEA and SEA • survey other agencies Determine training needs What programs do we need ● Describe existing programs ● Describe new programs needed <ul style="list-style-type: none"> • list existing facilities • additional facilities needed: recommend location and establishment ● Costs <ul style="list-style-type: none"> • current financing • future financing needed: projected 	<ul style="list-style-type: none"> ● Have all severely handicapped been identified? <ul style="list-style-type: none"> • Census • Social Services and other ● Are individual student needs being met <ul style="list-style-type: none"> • delineation of assessment tool (criterion measure) • delineation of timelines (previous evaluation) ● Needs assessment update
<ul style="list-style-type: none"> ● Establish leadership for conference ● Designate within the state department of education persons who will present to LEAs, etc. the described package of materials. ● Designate specialist in grant writing ● Form conference for assembling leaders, development of an ad hoc committee. 	<ul style="list-style-type: none"> ● Contact all relevant agencies to establish date and secure their participation <ul style="list-style-type: none"> Inform direct service education people medical doctors, other professional disciplines that serve severely multiply handicapped citizens, parents, civic groups, volunteer groups (e.g., high school programs, church groups) ● Convince funding sources of the need to modify strategies which prove ineffective in accomplishing stated objective ● Establish ongoing legislative committee which meets regularly with providers of special services

SPRING, 1974 (march-May)	SUMMER, 1974 (June-August)
<p>3. OPTIONS FOR UNSERVED CHILDREN</p> <ul style="list-style-type: none"> ● Evaluate present demonstration project in Casper schools ● Report evaluative findings from the Casper project and recommendations for state-wide program to state board of education ● Draft legislation re: severely, multiply handicapped class size proposal 	<ul style="list-style-type: none"> ● Submit proposed legislation to state department of education administrative council ● Submit approved legislation to attorney general for legal editing ● Submit proposed legislation to the state board of education ● Present the state board of education tentative policies to be used with proposed legislation
<p>4. WHAT IS RELEVANT EDUCATION</p> <ul style="list-style-type: none"> ● Appoint a committee to explore the competencies needed ● Hire a consultant with expertise in the areas of severely multiply handicapped and task analysis to head committee established ● Appoint committee to explore necessary changes in certification standards 	<ul style="list-style-type: none"> ● Review programs and literature concerning curriculum ● Establishment of a demonstration center
<p>5. PARENT EDUCATION—THEIR ROLE</p> <ul style="list-style-type: none"> ● State department of education initiate small group meetings-- local level: parents, professionals, combined, to determine mutual objectives ● State department of education devise and distribute a survey instrument to collect consensus of objectives from meetings ● Hold evaluation group meetings to determine relative consensus ● State department of education conduct a survey of current professional skills, standards, attitudes ● Initiate center for information collection-dissemination state level ● Explore fund sources 	<ul style="list-style-type: none"> ● Develop a state department level staff and program to eliminate professional's deficiencies and to provide for skill improvement as determined by survey instrument ● State department initiate locations of training in the state that will provide experimental content ● Continue information, collection and dissemination

FALL, 1974 (September-November)	WINTER, 1974-75 (December-Feb.)
<ul style="list-style-type: none"> ●File proposed legislative bill with legislative services agency 	<ul style="list-style-type: none"> ●Meet with sponsors of the legislative bill and appropriate legislative committees
<ul style="list-style-type: none"> ●Develop curriculum and strategies for pre- and in-service preparation ●Implement research on curriculum of the research center 	<ul style="list-style-type: none"> ●Implement the teacher preparation workshop at site where severely multiply handicapped children are available ●Development of final curriculum employing consultant expertise and research acquired at demonstration center
<ul style="list-style-type: none"> ●Summer-trained professionals replicate training to parents at local level ●Establish local centers utilizing existing services and facilities (i.e., mental health centers, county libraries, clinics, schools) ●Establish interagency committee in center ●Establish advisory council of parents to agency committee ●Develop meaningful and achievable programs to attract parents ●Make interagency participation part of job description ●To provide interagency recruitment of parents participation in advisory council 	<ul style="list-style-type: none"> ●Articulate and enable parent roles in service delivery ●Professional team provides, develops and carries out infant stimulation program to families ●In-service workshop ●Ongoing evaluation ●Instigate parent group; parent professional group ●Student-related staff policy of open invitation to observe and participate ●Activate resource pool of specialists and others ●Practice receptivity and honesty between parent and professional

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GOALS BY TOPIC FROM NATION-AT-LARGE GROUP

1. SYSTEMATIC DELIVERY SYSTEM

GOAL 1 DETERMINATION OF PHILOSOPHY, POPULATION TO BE SERVED, LAWS AND REGULATIONS, ROLES AND RESPONSIBILITIES

Spring: Promote discussion of the issues among professional special education state department officials, school administrators, parents of handicapped children and personnel of other agencies

Prepare a philosophy that is agreeable to those who will provide and receive services

Summer: Inquire about children with local welfare or service agencies

Organize a publicity program that will make people aware of the intention to provide service and encourage them to report the existence of children needing service

Fall: Recommend necessary changes

Have parents informed of legal issues in order to secure their support

GOAL 2 SPECIFY PERSONNEL, PROGRAMS, FACILITIES, COSTS

Spring: Identification of target

Summer: Identify existing personnel and determine training needs

Fall: Describe existing facilities and determine additional facilities needed

Winter: Determine current financing and future needs

GOAL 3 TO DEVELOP A MEANS OF ASSESSING THE CAPABILITY OF SERVICES TO MEET THE NEEDS SYSTEMATICALLY

Spring: Check state annual school census records

Check social services and other records

Summer: Identify criterion and develop method for evaluation

Fall: Provide for ongoing assessment to update needs

Winter: Continued assessment

GOAL 4 IMPLEMENT SERVICES FOR ALL SEVERELY MULTIPLY HANDICAPPED CHILDREN



Spring:	Delineate preliminary goals (based on needs assessment)
	Promote chosen program
Summer:	Review existing delivery models
	Make recommendations for pilot programs
	Promote chosen program
Fall:	Provide technical assistance for implementation of pilot program
Winter:	Lobby for enabling legislation
	Provisions for other funds

2. IDENTIFICATION OF CONSTRAINTS

Goals as they are rearticulated for federal government program planning:

- I. Establish a communication network for local-national and interstate information exchange: e.g., program description, funding, etc.
- II. Establish more clearcut lines of funding responsibility and accountability as determined by grass-roots participation in all program planning—short-range and long-range
- III. Establish research demonstration grants to develop an interdisciplinary curriculum for severely, multiply handicapped and an interdisciplinary in-service rotation program
- IV. Prepare a multi-media presentation on the severely, multiply handicapped targeted to all levels: e.g., civic groups, volunteer groups, schools, churches, etc.
- V. Require fiscal and program accountability
- VI. Allow for modification of specific program activities which prove to be ineffective in meeting stated program objectives

3. OPTIONS FOR UNSERVED CHILDREN

Recommendations to the U.S. Office of Education:

- I. Systems Delivery
 - A. Creation of new program delivery alternatives to stimulate and investigate



1. Services to rural areas

- a. A mobile mini-team to develop prescriptive programs for at-home, severely, multiply handicapped children and youth, and a team facilitator to train parents to implement the program

ACTION - Funds to demonstrate how to use the above model in LEAs and intermediate service units.

TOOLS -- Suggested resources are:

- 1) Telecommunication systems
- 2) Existing training package such as Portage Project
- 3) Video tapes

2. Funds to develop models for an information retrieval system at the state level for human program resources for the severely, multiply handicapped that is regularly updated and locally completed

B. Manpower -- Best practices in use and training

1. Define teacher competencies required to teach severely, multiply handicapped children. Use the competency definition
 - a. Force change in institutions of higher education training programs preparing severely, multiply handicapped teachers
 - b. Explore alternatives for teacher training: i.e., UAFs; voluntary agencies; state institutions, developmental day care centers
 - c. Stimulate research to determine empirically which competencies really result in child growth and development

See No. A2 Retrieval Information System for resources of how to do

C. Attitudes - Influence positive change in policy

1. Continue public relation efforts for acceptance and understanding and

how to influence curriculum for general education training to result in a change in attitudes among regular teachers

2. To stimulate medical school training programs to change attitudes of physicians concerning the ultimate potentialities of severely, multiply handicapped children and youth

4. WHAT IS RELEVANT EDUCATION

GOAL 1 INCREASE COMPETENCE OF TEACHERS OF THE SEVERELY, MULTIPLY HANDICAPPED

Strategy 1 **BEH disseminate literature on significant work done to date and scheduled for the future**

- Tactics:
1. Who is currently doing training and where: address pool
 2. Manpower pool of the experts in the field
 3. What funding is available to the state

Strategy 2 **By the end of 1st year, have developed system for subsidizing teachers, students and/or aides, host institutions for LEAs for 12-month work-study programs**

- Tactics:
- Select training institutions that
 1. Demonstrate practicum experience in field-based settings
 2. Propose cooperative institution/LEA demonstration centers for the education of severely handicapped
 3. Have a percentage of LEA training staff serving severely handicapped children

GOAL 2 IMPROVE AND DEVELOP INSTRUCTIONAL CURRICULUM

GOAL 3 DEVELOP STATE STANDARDS TO REFLECT NEEDS OF THE SEVERELY, MULTIPLY HANDICAPPED

Strategy 1 **Develop a national funding base to develop empirical data on essential competencies of teachers of the severely handicapped**

5. PARENT EDUCATION: THEIR ROLE

1. Parent inclusion (minimally 60%) and voting participation in awarding funds to all parent related service proposals—those parents to be representatives of established parent organizations



- II. Bi-annually BEH will be visited and evaluated by site visit teams composed totally of parents who are elected representatives of established parent organizations
- III. Annual Request for Proposal (RFP) site visits and evaluations will be made by site visit teams composed totally of parents who are elected representatives of established parent organizations
- IV. To provide funds specifically earmarked to encourage and support the development of parent training programs (RFP)
 - 1. To state boards to financially support local parent training efforts
 - 2. To local agencies or organizations (dealing with handicapped) to financially support programs (to include ARC, PTA groups, etc.)
- V. To support Closer Look in its efforts to make parents aware of existing services (specifically, media coverage of parent training materials)
- VI. To develop resource packets to assist groups in writing proposals to insure equal opportunity for all eligible organizations

**IMPERATIVES RESULTING FROM TOPICS DEALING
WITH THE SEVERELY MULTIPLY HANDICAPPED**

A wealth of information emerged from this conference. Parents, teachers and administrators everyone at the conference contributed insights and innovative ideas. The KMRRC staff members, who were distributed through all working groups, each recalled particular ideas that emerged time after time. From the dialogue and from the written workshop information, the following list of imperatives has been compiled:

I. Attitude Law:

- A. Develop a positive philosophy, attitude and commitment in order to build a delivery of services.
- B. Obtain legislated rights and services for the severely multiply handicapped, birth-to-death, with zero rejects.

II. Identification:

- A. Establish responsibility and accountability at program level for every identified severely, multiply handicapped individual.
- B. More effectively identify and appraise the needs of the severely, multiply handicapped population.

III. Services/Structure:

- A. Establish inter-disciplinary: terminology and resource cataloging, leadership development, teacher training, curriculum sharing, working conferences to enhance attitudes, corporate decision making, lobbying, etc.
- B. Avoid inter-agency duplication, fragmentation and bureaucratic weightiness.
- C. Establish comprehensive needs assessment of available service resources at every level.
- D. Reassess the compound and complex problems relating to serving the severely, multiply handicapped in rural remote areas.

IV. Training:

- A. Evaluate existing programs and develop pilot programs that include evaluation components.
- B. Identify methodology and tools so committed groups and individuals can



mobilize their concerns even when they are without adequate funds and programs.

- C. Obtain training resources that exemplify the current innovations and trends in special education.
- D. Develop appropriate incentives to recruit qualified severely, multiply handicapped instructors.
- E. Match preservice training with actual competencies needed to serve the whole person.
- F. Facilitate the development of training programs by joint efforts of LEA, SLA and university personnel.

V. Parents/Community:

- A. Involve parents and providers of services (teachers, etc.) in all steps of the decision-making process, from the funding and coordinating agencies to actual service to the child.
- B. Raise the level of community awareness to acknowledge and enhance the LEGAL and PERSONAL rights of severely, multiply handicapped and parents.
- C. Train the family unit so that parents and siblings can perform early intervention.
- D. Develop alternatives for respite care and crisis intervention.

VI. Communications:

- A. Extensively permeate the media as a means of improving services for the severely, multiply handicapped; improve communication and cooperation of those charged with dissemination of information to the individual at every level.
- B. Provide a structure and methodology to foster open communication between professionals and parents of severely, multiply handicapped.

VII. Funding:

- A. Develop a clearer image and method of identifying, utilizing and expanding public and private funding and service sources.
- B. Encourage cooperation in fund sharing and service interaction.

WEDNESDAY MORNING KEYNOTE ADDRESS

PAUL THOMPSON

Thank you, Judy. I am delighted to be with you today and particularly honored to be here representing Dr. Martin and to extend to you his very sincere greetings. He was delighted at the outset when he learned that the conference was being planned, and, as Judy has indicated, has keen interest in this field. Unfortunately, because of the nature of his position—being in such a viable spot in the national scene for education of all handicapped children—he must be immediately on the scene when urgencies arise. He has to extend himself to areas of severe need and so we might say that he is on call almost twenty-four hours a day in defense of the handicapped child.

The comment has been made, and rather appropriately so, that a prophet is not without honor save in his own country and his own home. So when Dr. Martin asked if I would stand in for him at this occasion, I recognized that that would be a problem here. I envisioned in my mind how this might appear in the local papers. It probably would read something like this as a caption: "Native Son Named Severely Handicapped Head." And then as a byline to this great headline, it could have read: "In the otherwise turbulent sea of recent bureaucratic blunders, recent selection of a leader for severely handicapped children and youth termed a natural."

Now I would like to address in a rather oblique manner at the beginning the topic that Dr. Martin was assigned. The topic was "What Should Federal Education Policy Include for Severely Handicapped Children?" I was very delighted, and I should say, in most sincerity, that this is one of the most significant conferences to deal with the specific topic of severely handicapped that has been held anywhere in the United States.

Recently, after being called to the position as chairman of a task force in the severely handicapped programs, I was delighted to find out that one of the significant things would be happening in my home state, so I signify this as being one of the very early and very significant steps which most certainly will have a pronounced effect nationally. It may be considered by you as a regional event, but the dimensions of this are much more far-reaching in scope than the confines of this region. So, I commend you.

Now, I would look at the conference objectives in this light. It's definitely a working conference to deal with specific issues and, in this regard, to take within yourselves a survey of the needs of children whom you may call severely handicapped. Then you would be making a study within your resources: What are the available sources of funds? What are the available strengths in manpower that you have at your command? Then you would be in the process of developing long-range and short-range goals to impact the educational activities and training activities of this type child. And then you would be looking for the development of incentives and the skills that need to be included in the capabilities of individuals who bring positive impact on this type of child.

Now, where does the national picture fit in all of these? Possibly it would be well to approach this by

looking at the initial inception and reasons for forming BEH, the Bureau of Education for the Handicapped. Quite some years ago, in 1965, the nation's lawmakers took a concerted look at the needs of children who they termed disadvantaged. And, as a result of much discussion and much controversy, there emerged the first major act of the Congress to impact into the needs of the disadvantaged child. And, following closely, was legislation enacted to direct attention to other areas of those who could be considered disadvantaged. Very shortly after the passage of what we now know as Public Law 89-10, the same Congress convened again to consider amending their work. This is one of the few incidents in history where the same Congress recognized wherein they had fallen a little short. I think this is quite significant because they took steps immediately to realign their directions. They came forth with some interesting statements. One was to indicate that the term "educationally disadvantaged" included handicapped children. Now to some this may seem a very insignificant development, but to others this was a major milestone in bringing impact to handicapped children. Subsequently there was passed what was then known—by the nature of the whole act—as the national disaster act. The only thing that was not a disaster was that it included a very brief paragraph, the Amendment to Title 1, which brings special monies—federal monies—to assist state-operated and state-supported schools for handicapped children. We refer to the whole act now as Public Law 89-313, amended, General Title 1, which has over the course of years brought money to the states for support of that type of education.

Following that enactment there were other fragments of educational bills which brought public interest to bear on the training or the manpower resources for handicapped children.

And, after a time, there was enacted a bill known as the Education of the Handicapped Act, which brought together under one legislative package the federal thrusts for handicapped children. Included in that particular act was the provisions for establishing a Bureau of Education for Handicapped Children, an organization that would have the responsibility to direct some national policy and to help influence, on a national scope, the impact of services to this type child.

So the Bureau was organized in January, 1967, and from that time forth has been making an attempt to satisfy its national commitment. It was then divided into various sub-units within the Bureau, so that the work of providing national direction and assistance to handicapped children could be more effectively carried out. And so the Bureau existed at the outset with three divisions. One dealt with the specific needs of services—direct services to children—and became known as the Division of Educational Services.

Under the scope of this particular division, the Bureau continues to provide direction to the states; at least the Bureau thinks it provides some direction. The service components include such things as Public Law 91-230 which includes the Education of the Handi-

capped Act, and a part of that, Part B, Education of the Handicapped Act, brings services and monies to the handicapped child in the local education setting and to the state education agency. Another part of that act, Part C, provides funds for education of the children who are early childhood level. Another part deals with Regional Resource Centers, a segment which has been a source of funds for funding this excellent organization, the RMRRC, whose hospitality we presently are enjoying for this conference. One other section of that deals with the deaf-blind population and intends to bring impact on that type of child, wherever he or she is located, bringing the greatest amount of services to bear there. Another package became known as media services and caption films. And then to the resources that might be available in learning disabilities.

One of the other divisions of the Bureau is the Division of Training, which provides for the development of manpower to meet the needs of educational services to such children. And then we have the Division of Research, which has the very exciting responsibility of bringing to the forefront innovative ideas in terms of new approaches, more effective means of intervention in the educational efforts of children.

Thus, we have a Bureau going essentially—I was going to say in three directions at the same time—but essentially with three major emphases: services, the training of manpower and research into areas that have not been explored and, hopefully, some that may yield even greater results with national effort.

So much for the structure of the organization. What about the over-arching goal of BEH? And I think we could very easily review this because this is a most significant view. The Bureau recognized that while we could impact on individual children, the great need had to be the over-arching goal which was established and so worded here: To provide equal educational opportunities to handicapped children which will enable each to achieve his fullest potential. Now, obviously a goal of that dimension would be mere words unless it were placed into more specific action, and it is exciting to note that at this conference you'll be dealing with global issues. Then, because of the significant planning that has been done here, you'll be coming to grips with the ways you can design objectives, and you can develop strategies to reach those objectives, and finally impact with activities or tactics in order to come to grips with how you finally reach the overarching goal.

Now, let's view then, in more specifics, what the BEH objectives are. These have been indicated on the global scene, and of course you recognize that with many of these the Bureau itself cannot have great bearing upon them. The Bureau essentially sits back there in an office in Washington and we accumulate statistics. These statistics are the life blood and the effort of you great people in providing the services. Though you might say we are trying to take credit for your work, this is not really the case at all. We're trying to make a visible noise nationally that says,

"Look, Congress, these things are being done and these things are possible because they are happening out there where the action is."

And so the first objective here, as you know, is to secure the enrollment by 1978 of eighty-five percent, which amounts to 850,000 preschool-aged handicapped children in federal, state and local educational programs. Now, to implement that the Bureau, in addition to accumulating statistics on what the action is like, what you are doing, has made an effort to bring impact on early childhood education. I'll touch on that issue a little later.

The second objective established for national direction: to assure that every handicapped child is receiving an appropriately designed education by 1980, with eighty-five percent of them reaching that by 1978.

The third: to assure that, by 1977, every handicapped child who leaves school has had career educational training that is relevant to the job market, meaningful to his career aspirations, and realistic to his potential. The Bureau has locked arms with the Bureau of Adult Vocational Technical Education to bring some very intense impact into the field of career education. As a result, we have seen some exciting efforts expended where these two forces have joined together for a desirable end product. And such is the case now with the set-aside monies under Voc-Ed, where those monies can be made available to be used in connection with the state and federal and local monies to bring impact to handicapped children.

Now most of these issues, as you recognize, address all the population of handicapped children. But I would want to point out these generalities to indicate that within all these parameters lie the potentials for the severely handicapped.

Objective number four: to assure that all handicapped children served in the schools have trained personnel competent in skills required to aid each child to reach his full potential.

And, finally, the fifth objective and the one that brings me great excitement and interest because of my recent assignment, but particularly because I think this has been for such a long time a forgotten area: to enable the most severely handicapped children and youth to become as independent as possible, thereby reducing their requirements for institutional care and providing opportunity for self-development.

These to me seem to be great objectives. When applied to a state level, they could be equally viable. They could be equally viable on a local basis and when approached in a meaningful manner, as you people will be doing in the course of this conference.

Now, in order to give some direction to all of these thrusts, the Bureau developed a number of task forces. In doing this they developed one that targets on early childhood, the handicapped child at the early age. And this particular task force attempted to marshal the resources of the Bureau and direct national effort for early childhood needs.

The next task force that was enacted by the Bureau dealt with overall services, and we call it the full services task force. This task force has the responsibility to look at global needs of handicapped children, and to set some national directions.

Then there is a special task force dealing with the vocational or career educational needs of handicapped children. This task force has done a lot of its work. Then there developed the most recent one—on severely handicapped. So essentially the Bureau has brought together people from the different divisions, with their individual expertise, and they were given the assignment of the charge to do the following things:

First, to develop planning in these specific target areas—direction-setting, if you would, or at least sensing the pulse of where the action is and reporting back to the Bureau.

Now to deal more specifically with the issues concerning us this day and for the next two days, the issues of the severely handicapped child. The task force for this particular effort was pulled together about March of last year and given the basic assignment I've indicated.

The composition of the particular group represented each of the divisions, and particularly those individuals with expertise working with severely handicapped. The charge, then, was to develop some national planning for BEH and for the nation; to determine what BEH is or was then currently doing in this field; and then to determine what the national needs appear to be; the cost relevant to those needs; and finally, to see what the Bureau could do as an agency to bring some national visibility and finances to go with these kinds of efforts. And now, more specifics of this particular task force.

As the task force began its action, it started on a survey of what is happening in the Bureau—not really in the Bureau—but what is really happening where things are going on. The task force looked into various activities that were then funded, and the various federal programs supported at the Bureau, and determined that there was already a considerable effort being expended. They looked into Public Law 89-313, monies to handicapped children in state-operated and state-supported schools. They found that approximately ten to fifteen percent of the money was being expended on specific projects with severely handicapped.

And then they looked at Part B, Education of the Handicapped Act, and found money being spent there by the local community agencies, and were delighted to find that. We looked into other programs and found that under program Part C, early childhood education, quite a bit was being done on severely handicapped. And then we found that in the Division of Research, interesting developments were under way on the national scene. Subsequent to the survey, we determined that the needs of severely handicapped children were just being looked at and, really, despite the monies being spent, a token gesture was being

given in that direction.

And so one effort was launched, in the form of a special research study. A contract was accepted from an agency in Cambridge, Massachusetts, and this agency is now making a study. The study itself is going to do several things. Actually it has done part of its work already. The first aspect of the study that was funded by the Bureau, was to produce a literature inventory and an annotated bibliography of information relating to definitions, program activities, policies, procedures, implementation activities for severely handicapped children. That process is already partly completed. They developed their research study, they have already published their literature search, and these will be made available nationally after having gone through all the orders of editing and such that need to be done.

Another aspect of their assignment is to make a national survey of all programs serving handicapped children. Some of you may have seen these survey instruments. They are trying to determine in what manner you are providing service, if you are, to severely handicapped children. And so it will be attempting to identify localities and types of educational delivery systems for working with this type child.

In the third aspect of their program, after locating the spots where the service and the action are, they will make a rather intensive investigation into those specific programs. They will then develop a resource document which will include a great variety of programs, various intervention methods, and the approximate costs for implementing them. This is the kind of personnel needed as evidenced by the programs then operating. The final effort on this contract will be to site visit 100 selected programs, some in the day care program, some in interim care placement, some of them in a residential type setting under Department of Public Health or Public Welfare or some noneducational state agency, and then to visit residential type settings. In short, they are going to attempt to see the wide spectrum of programs. Then they will be writing case studies in some depth. And this material will be made available for review and distribution to the nation. So we are looking forward to that.

Now, the next effort that the task force became involved in was coming to real grips with what it is we are all about. One of the first things we recognized was the need to determine a definition. We were talking about severely handicapped children and everybody used that term. So, we said, that's simple. Let's define severely handicapped. Well, three months later we had decided that that definition was not simple. We had met numerous times, we could not come to agreement, so we finally said, look, we could spend our entire time coming to first one meeting after another, and so we took an interim step. Now,

maybe this is a significant thing, because I believe that we could waste a great amount of creativity if we attempt to have everybody going the same direction simultaneously. Sometimes we need to have the fortitude to establish--on the basis of firm conviction--some things that enough people agree are in a positive direction. And then, making judgment after. After all, it is better to criticize something where action is taking place than to criticize the lack of action because hopefully something good will take place if something good starts. And so, the definition we came upon was one in the point of reconciliation between these behavioral modification specialists and those who liked definitions per se.

Let's review now the definition we developed. Now, admittedly some of the children you would like to call severely handicapped children may not fit in this category. But we felt it is better to try to serve some within the limited confines of the definition than to try to serve everybody and miss all of them with the effective programs they need. So the definition:

A severely handicapped child is one who, because of the intensity of his physical, mental, or emotional problems or a combination of such problems, needs educational, social, psychological, and medical services beyond those which have been offered by traditional regular and special educational programs, in order to maximize his full potential for useful and meaningful participation in society and for self-fulfillment.

Well, if that doesn't read like a federal regulation, we've all missed our callings. Within the confines of that definition, however, is embodied a great concept. Namely, what we're looking for under this definition, this umbrella statement, is children who have multiple learning problems. And as a result of the multiplicity of the learning problems and the impingement, one upon the other, there falls a need to work with this child from more than one educational skill. As a result, trying to define this to satisfy those who hate categorization, such children include those classified as seriously emotionally disturbed, schizophrenic and autistic, profoundly and severely mentally retarded, and those with two or more serious handicapping conditions, such as the mentally retarded deaf and the mentally retarded blind.

And now we go on to talk about the behavioral characteristics: Such children may possess severe language and/or perceptual cognitive deprivations and evidence a number of abnormal behaviors, including a failure to attend to even the most pronounced social stimuli, self-mutilation, self-stimulation, durable and intense temper tantrums, the absence of even the most rudimentary forms of verbal control and may also have an extremely fragile physiological condition.

That satisfied the need for a definition and, from that point, the task force went on to look at some of the specific goals of the Bureau in terms of what should we do for the severely handicapped.

So we developed some goals. These goals were designed to provide national direction to this target

population. The first objective was to design and implement services for severely handicapped children and youth. And through this chart we attempted to show that there was a great number of children--namely 1,054,000 children at least, in the category that we defined as severely handicapped--who are now unserved. Now, if you wonder where we got our data, this is extremely reliable. We took it from the information we got from the states. The states got it from LEAs. The LEAs made it up in the back room somewhere, and now it has acquired national prominence because it's been validated on the basis of the grass roots input.

We then said, out of those children who are now in such need of services, let's take an objective and, to provide some input, say that we're going to provide screening and diagnostic services and prescriptive services to at least 52,700 over the course of a year. Now these are global statistics. We may never achieve them. In fact, we'll never achieve them until we find out what's really happening.

Then we said, of that group who are going to be identified and have diagnostic services provided and prescriptive schemes given to their educational effort, let's target in on a number of that group, namely ten percent of them. And that would bring us to 5,300 such children for whom there will be designed an effective intervention system to provide training and/or education for their needs. And then we said, let's take another ten percent and this year bring tremendous impact in the delivery of new services to 5,300 such children. Now, you wonder how we're going to do this. Well, of course, it's going to happen through your efforts and we'll talk a little later about an RFP--request for proposal. The Bureau decided they are going to have to bring the interest up in this field because there may not be that much attention given if we didn't. So we decided we'd have to help develop our own objectives and then help reach them by some national effort.

Objective number two was the improvement of services to severely handicapped children now receiving some services. So we said of the 230,000 severely mentally retarded and the 9,000 multi-handicapped and the 109,000 seriously emotionally disturbed, we're going to take out a segment and say of that total population, one-tenth of them would have a much improved educational intervention program. We felt that was pretty safe, because knowing the professionalism and the great drive that was in the minds and hearts of individuals such as you, we thought we could bank on you for filling that objective. We're just merely saying that you're going to do a lot better with at least one-tenth of those you are working with.

And finally, objective number three--the successful employment of severely handicapped children and youth. Now we looked at a population, say, of 350,000 who are now getting some services and, say that we are going to have at least one-tenth of them successfully employed. That can be a fantastic objective, but we look to these as realistic efforts in the scope of the nation. If those can be the national objectives, then what has to be done, of course, is to

see how much of that total challenge can be taken by individual states.

We then come to a special effort the Bureau launched in what is known as a request for proposal. This was entitled Programs for Severely Handicapped Children and Youth, and was announced nationally about the 6th of January. It said in some rather obscure terms that the Bureau of Education for the Handicapped is interested in funding programs to impact on severely handicapped children and youth. Approximately ten programs will be funded. We were unable to tell how much money we were talking about, we said think big, cost small sort of thing, but to think big. And so we issued that and it was mailed out on the 25th of January to everyone that had requested copies of this and to a few who hadn't requested them because we had accumulated a list of people we knew were interested. Unfortunately, we failed to tell them that we knew they were interested and they got copies of this document later and wondered what on earth it was. It was a sheaf of paper and halfway down we finally told them what was really happening. The first twenty-six pages told them how to get through the government red tape - red tape recording, should we say. At any event, it told them how to get through some of those procedures. Then finally the essence of the effort was explained in what they call, would you believe, Attachment A? In any event, the impact of the task force efforts was embodied and boiled down and condensed into that little package. It was the thrust we were trying to provide. We said do your best and most exciting things, but let us know soon what you'd like to do and how much you think it's going to cost you, and send it in. Well, some have done so. We gave everybody the fantastic amount of thirty days to respond. As of 3:30 Monday, this week, 41 proposals had come in from the nation. We're thrilled because 41 people in very diverse areas - fortunately we have some from the areas represented here - but from 41 in the whole nation it's great that one came right from the Salt Lake City area. I was delighted to see that. We have a number of universities involved; quite a few universities were invited to do this. We have about nine different local educational agencies all over the United States, one being here. We have State Departments of Education excited about it, and now those who have applied are, I guess, all excited, waiting until we can find out which ones will get the money. They came in interesting size boxes - in various sizes of packages. One came in a box that was as high as where I stand from here to the floor - copies of their proposal. So there were differences in the kinds of things that they planned to do and also the enclosures that they inserted. People sometimes tend to send you a little bit of everything that they have been doing and confuse the issue.

The next thing the Bureau attempted was to launch another RFP, and this deals with telecommunications for severely handicapped. Now, here's a very special effort. This one is asking agencies or organizations to fund viable programs for severely handicapped children who are homebound for a period of time, not necessarily chronically there, but for an interim period. When they leave an institution, they may have to be

home because of a fragile health condition, they may be there for a week, two weeks, and we are looking for a viable intervention system that can proliferate the educational success given when the child was in another appropriate educational setting. To say that when he gets home the impact will not stop. He will continue to grow. That was the philosophy.

Now, we had a little problem about the RFP because, unfortunately, we didn't announce that it was for non-profit organizations. As a result, a lot of the commercial organizations that have telecommunications as a prime media effort were unable to bid, so they had to get in cooperative efforts with educational systems, and we have now on hand 17 offers to do this for a national effort. We'll let you know a little later what's developed here, but we thought you'd like to know.

Moving onto other areas, I think it would be appropriate for us to now look back to the central theme of the meeting today and to look at the reasons why, again, we are convened and the specific area now that was assigned to me of why or what the federal effort should be in setting educational policy to include the severely handicapped. Well, I think I have tried rather obliquely to address that by stating that the Bureau established and accepted the responsibility for setting some national goals, national objectives, and is trying to help implement them by providing some funds. So it tried to help by working in the areas of manpower, research, services and to help with finance. Then it has attempted to look at the development of policies and practices.

How has the Bureau attempted to do this? Well, you may say this is a little subtle to indicate that, but in the writing of the RFPs there was spelled out what the Bureau looks at right now as some viable ways to plan for the needs of severely handicapped. I'll just mention a few.

The first we recognized as of prime importance is the planning aspect. Under the broad category of planning are the needs to identify what the problem is - to define the dimensions - to define not only the numbers of children, but also their specific learning needs. Second, to find out the available resources; to categorize them, to list them, catalogue them as well, and then to try to see how nearly the needs can be met with available resources. Then we were looking at a third, for the development of a comprehensive statewide plan. Now this was built into the RFP so you can imagine as you will how we were attempting to suggest some means of procedure here. My colleagues presenting today and in the following days will have other great methods of suggesting how this might be done. But we were looking for a coordinated statewide plan so that the services to severely handicapped would not be a little hauble or parcel all by itself, isolated, but would rather be an integral part of the rest of the system. Next, we were looking for an operational plan that was well thought through. The beginning of service; the entry of the service delivery component; and finally to include a literature and research review; the evidence of coordinated planning from all the affected agencies; the utilization of widely-

based advisory committees, showing parent input, a representation from handicapped individuals, those in the target areas. And then we were looking to a second major effort—that is, the delivery of services which would include not only the identification of children individually—those needing services—but the findings of their diagnostic needs and then making prescriptive services clearly known. And then, the implementation or the delivery of the services. This would include the identification of models for delivery, the content of service elements, the identification of courses of study or the development of them, and finally an accountability which would include a very careful and ongoing evaluation effort.

Now, with all of this, you and I are at the vantage point of looking toward the future. Interestingly enough, the future begins today. It does not have to wait until tomorrow. It begins today. So as we begin this conference we are at the most exciting time of our lives. Someone has said that today is the most exciting day of my life because it's the first day to my future. Now if we look at the vantage point, we would say, we start right today and, in the lack of remorse for what we may not have done in the past, we identify the threads and the pieces and the elements where we need to pull together and tie beautiful bouquets, rather than knots, in the educational effort.

What are some of these? And I'll just briefly mention some input that I have noted in this area. I'm remembering now an individual boy who was entered into the public school system in San Francisco some time back. The teacher was advised before this child entered that she was to receive a blind handicapped boy into her class. He also had a little travel difficulty. She was a very alert, eager individual, but this was even taxing to her. She thought, do I have the ability to encompass within the scope of my planning here, and within the educational scope of my setting in the school, this deviant child? But then she said, true to those who are imbued with the special educational effort, that she would do it—actually she didn't have any recourse, it had been assigned—but she'd made the best of it. So, she said to the class that afternoon, "Boys and girls, Bobby is coming to school tomorrow. He's a new boy here and I hope you'll be friendly with him because he will not know you until you've introduced yourself and if you can be friendly with him you'll like him and he'll like you. He will need to know where the things are in the room, where we keep our crayons and where we keep the various supplies. He'll need to know the way to the bathroom. He'll need to know the way to the playroom and the things that we do there and the outside playground. And just make him feel friendly and belong to the group." And after she had finished that she said, "Oh, and by the way, Bobby is blind." She said nothing further, but the next morning, about 10:00 o'clock, into the room came Bobby, brought by the supervisor. The teacher introduced Bobby to the class and he was presently busy with the boys and girls in various parts of the room. They were doing their job—each one was trying to do his or her job and, typical of children, accepting as they are at that age, he was soon taught where all the different things were in the room, where

the restroom facilities were, where the playground was and where all the exciting activities take place at the school. He found himself included in the circles of activity. So as the school activity moved through the day, the teacher became almost unaware that Bobby was in the class. At the end of the day, she suddenly recognized that she had had Bobby there all day and had paid little attention to him really, because he had been so busy with the children. "Oh, where's Bobby?" she said to one of the children. "Bobby?" he asked. "Who do you mean, who's Bobby?" "Oh," she said, "the little blind boy." "Oh," the boy said to the teacher, "Teacher, Bobby is not blind anymore. He knows where everything is." What a great perception of how the handicapped child can be a part of the group.

I remember a great student who went to the Utah School for the Blind some years back. She was visually impaired, but she had also a severe mobility problem. She had had a tubercular condition that had left her unable to control her actions. After she had spent some time in the hospital and had some therapy, she went back to the school and attempted to be integrated there, but she was a little bit out of everything. She not only felt like she didn't belong to the school, she didn't feel like she belonged to the home or any particular environment. So she accumulated a little bit more of *avoirduois* than others and her dimensions were even more difficult for her because as she gained weight she lost more and more mobility. Then she learned how to use crutches. But I remember Judy as she maneuvered up and down the halls on her crutches. She would get out in the middle of the hall and then she'd kind of lose her balance momentarily and she'd sway way to the side, almost to the point where she'd almost go down, and anyone looking on would be sure that the center of gravity had long since brought into order its act and she would collapse onto the floor. But, for some reason or other, she had this sort of motivation to stay up and she never fell, but she just looked like she was going to fall and you'd say it was defying gravity. Well, one day Judy made a grand appearance. You see, she had had the experience of working with a special little group of young girls at the school and they had been taught homemaking skills. And they were brought into a special fashion show. The blind girls were going to exhibit the gowns they had made, that they had sewn themselves. What a thrilling experience. Well, Judy's time came to model her gown and there was a small audience and there was a little stage and Judy had been instructed carefully how to get to the center of the stage and how to turn around—can you feature that on a pair of crutches, modeling her gown—and then to go off, exiting very gracefully. Judy got to the center of the stage and she looked lovely. But Judy swayed a little bit—this was the usual hall act. We'd seen this before. She swayed way to the side and it did look like she was almost going to go down, but those of us who knew, recognized that the center of gravity was being defied again, and this was another incident. But before she quite got to her posture, someone in the audience determined that the need was very apparent and so she dashed bravely forward as the Samaritan of the day and grabbed hold of Judy and righted her up and helped

her so she could get from the center of the stage to the wings. And I can still remember seeing Judy in the wings, weeping because the day of her challenge had been shattered. Somebody who had recognized what she thought was the thing to do had done just the wrong thing. How important it is that as educators we recognize what are the right things. And how important it is that we do the right things for the right reasons.

And just one more. This boy Jerry was not wanted at home. When the parents arrived with him at the school, the mother said, "Of course he will stay at the dormitory, will he not?" and I said, "No, not really. We like to have the boys and girls who live in the area come to and from the school every day and live at home with their parents." The mother sat back in a great deal of horror and she said, "Jerry can't stay with me at home. I don't have a bed for him." I could hardly believe my ears. "You do not have a bed for Jerry?" "No, I have no room for him." "Well," we said, "isn't there some arrangement you can make?" We went through a number of activities, seeing if there wasn't someplace but, literally, she had no room for Jerry. Not because there was not a bed. There was no place in her heart or her countenance to tolerate a boy that deviant. He was not only visually handicapped, he was emotionally disturbed. And you can imagine why. This severely handicapped boy, when it was recognized that he even needed a new home placement, that was done and it was effectively done. There was an intervention in his life, that kind of viable approach that you people can give. That boy righted himself. He was taken to a foster home day after day, night after night, and came to school and his progress continued in a great manner. What a thrill it was to receive through the mail, after being away from the school for quite some time, an announcement of that boy's graduation from high school. Someone who had supposedly been severely handicapped, visually handicapped and so severely emotionally disturbed that he was unwanted, there was no room in the inn for that boy, had finally found a place in society, because someone cared.

Today the someones who care are you. I challenge you and me to accept this moment of the day as our first step into the future to allow into the activities of our lives the needs of the severely handicapped child, and to progressively work for their better good. Thank you.

SEVERELY HANDICAPPED CHILDREN: RIGHTS AND RESPONSIBILITIES.*

DR. EDWIN W. MARTIN

Thank you, Judy, and I'm sorry I had to stand you up, but we've been in the process here of trying to get all of our grants and contracts approved and over to the grants and contracts office, and also working on the budget and the Commissioner has put some time pressures on me; I just needed to stay here. However, those are productive activities and I hope you'll forgive me. Also, I feel good knowing that Paul Thompson is there with you and knowing that he can give you the kind of specific information about our activities that I know people are interested in. But I'm sorry to miss being in Salt Lake again, because I have some interesting memories of Salt Lake City.

The first trip I took when I first came to work for the Office of Education was to Pocatello, Idaho, and actually at that time I was working as a kind of a consultant for four months in a training program of the Bureau. Mike Marge was the director of the speech and hearing unit of that program and we were dividing up trips and, as I remember it, he went to Hawaii and I went to Pocatello, Idaho. Something of that magnitude. But anyhow, I had to go into Salt Lake City and stay overnight and then take a plane up to Pocatello. I was kidding with Ted Bell, who I know many of you know, about that recently. I told him the wonders of Salt Lake City in 1965 were that there was water running down the street, that at 8:00 or 9:00 o'clock on a Wednesday night the town was very quiet, and that the only movie playing was Annette Funicello in "Beach Blanket Bingo." All those things have given me a kind of bizarre recollection of Salt Lake City, and I was really ready to bring it up-to-date. So, I'm sorry I didn't get the chance. I somehow have the feeling that my impression is atypical.

The area of multi-handicapped or multiply handicapped people has been a concern of ours for some time. Paul, as many of you know, heads up our program of assistance to state-supported and state-operated schools. Ever since it began in 1966, we've really been encouraging the states to deal with severely handicapped and multiply handicapped children in those programs. And many of the first programs, education programs, within state hospitals for example, were begun under what we call that 89-313 money. Some states used the funds to provide services for the basic population in the hospital. Others have tried to develop special programs, for example, for multiply handicapped deaf children, such as deaf and emotionally disturbed or deaf and retarded; some have used them for cerebral palsied, mentally retarded youngsters. In a number of instances, the states have used funds to begin programs for those youngsters who, while residents of the state hospital system or the state school system, were not getting educational programs. Many of the advances that are still avant-garde have been made under that federal program which is now almost a decade old.

At the same time the national pattern of services for multi-handicapped children, severely handicapped children, has been very much a pattern of exception rather than the rule. Over the years a number of parents have spoken to me as I have gone around the country and told me about the exclusion of their children from programs, about the letter sticks in my mind from a

lady from Iowa who wrote me and said, my physically handicapped deaf child is turned away from the program for physically handicapped because she's deaf and she's turned away from the program for the deaf because she's physically handicapped. Another lady from California wrote me about her autistic child and some of the problems she had, and on and on in every state.

There are many such examples, so that in the last several years we felt that we wanted to try to focus more attention on this population. As Judy can tell you, I guess two years ago at just about this time, I wrote to the directors of the Regional Resource Centers program suggesting that they try to focus more attention on the severely handicapped population within their service load. So, this background is to say to you that the federal government is interested in this area, this interest has existed for a long period of time, and it's reflected across our programs. Our most recent focus on it is simply a way of trying to speed up the actions that the states and locals are taking. Philosophically, it's a logical outgrowth to our deep feeling that each child can profit from education and that every child should have an appropriate education. A national goal of that kind might analyze where the failures are in our system now.

Now, you know as I do that there are two broad classes of failure. One is that there are many mildly handicapped children or even moderately handicapped children who are in the school system now and who present a pattern to the teachers of requiring help. One of the places I think this has been illustrated is in the Rubin and Balow study reported in the Exceptional Child several years ago, in which they reviewed the population in the Minneapolis area, and they identified children that teachers felt required special assistance. These children were identified along a continuum of various kinds of referrals. Some were, for example, not promoted from kindergarten to first grade because they were not ready. Some were referred for speech therapy, some were referred for special education placement, some were referred for guidance-counseling placements, some were referred for reading instruction, some were left back if they still had a left-back system, and on and on. That population, you see, was much larger than what we think of as handicapped population, ten percent of the school age children. They discovered that between a third to forty percent of children over a period of time fell into such a category. That is, that the assumption that the normal population of the school was comprised of ninety percent of people who have no problems and ten percent who are handicapped is really a myth. That's a kind of a fallacy. Not all these children are handicapped, but they require and are identified by teachers and others as requiring a special modification of the school programs. So perhaps the largest population of handicapped children whom we fail is this group of children who have very special learning and behavioral needs and who exist in the schools in a relatively unserved state.

Then there's another population which is excluded from the schools altogether. And our best guess about that population is that it is a half million children, and it may even be a million children. By the very nature

of their being excluded it's impossible to count. But where states have really searched out and tried to find such children, the kind and the number of children they find who are either excluded from the schools or who are on the waiting lists for institutions or school programs, who are for all practical purposes excluded, are of the magnitude that allows a projection of one-half million or more of these children. So, when I start thinking about the failure of the United States to provide equal educational opportunity for handicapped children, the first place I focus is on these two sets. Those kids who are sitting in school and whose parents get notes home ranging from the fact that Johnny won't sit still to Johnny could do better if he tried harder and so forth and so on; to kids that are just flatly told, look, we don't know what to do with you, youngster, and we don't have any place for you in our program. We hope we will next year.

These are problems, then, that we've got to come to terms with. And the Bureau will try to focus attention on both of those failings. Now, two other Bureau priorities have emerged which are kind of logical extensions of this position. One is our focus on preschool children, because here too we have enough evidence and we have enough intuitive knowledge as professionals to know that starting programs for these youngsters has accelerated their language growth, their cognitive growth, their psycho-motor skills and so forth. We've seen that demonstrated. I think we all believe it, and we also know that it's tremendously beneficial to the child and it's cost beneficial to the school systems, and to the state in reducing later costs for rehabilitation to welfare and institutionalization. For a number of reasons we have to provide preschool education, yet we haven't and the immediate reason is "we don't have enough dollars to do that." This reason only makes sense if you don't take into account what the long-term costs will be which are going to use up those same dollars later on. We are trying to focus attention on preschool programming and to point out the benefits to society in terms of increased potential the children will show, the reduction of disability.

I talked with a fellow that some of you may know, Dave Weikart. He's a researcher up in the Michigan area and his project is one of many, but it kind of gets at what I'm talking about. They did a research study on a population of children that they predicted would be retarded and would require special education. They made that prediction on the basis of the fact they were of low socio-economic groups and they were part of families that already had brothers or sisters or parents who were judged to be retarded, and by the way I'm not giving you a fair research report because I haven't studied the data; I'm just trying to give you an illustration which you don't want to take, you know, as scientific testimony, but merely to illustrate the kind of programming I'm talking about. Well, anyhow, those youngsters received two years of preschool programming and when they were in school they were followed up a couple of years later - I'm not sure if it was second grade or third grade - and at that time thirteen percent of this high risk population that had had preschool training, were in special education programs, which is still a high rate and tends to confirm the fact

that this was a high-risk population. But there was a control group, picked randomly from the same population, who didn't have the two years of preschool work and thirty-three percent of that group was in special education programs. Okay? So the point I'm making is that the costs of not providing that preschool program are twenty percent more children in special education, costing \$1,500 or more a year to the schools. So it's clearly demonstrated in that one study alone that if they had given those two years of preschool instruction it would have come out a lot better for the children and also in terms of costs. Some of these youngsters may be in special education for twelve years.

Now, I have another study that I'm familiar with. Same kind of analysis with kids who are identified at age three as having a learning disability. Let's assume they all had mild neurological problems, or a pronounced speech and language retardation, something that will positively identify them at age three. And the same type results occurred. They had the two-year program, down in the Houston area this one was, Dr. Tina Bangs reported to me. At the end of several years, two years preschool, two years followup training, two-thirds of that population was reading at age level. That was compared with seventy percent of the "normal" population reading at grade level. So you really only lost three percent, which may not even be a significant difference statistically. The untreated population, the number reading at grade level was very small, I've forgotten the percentage now, but I think it was fifteen or eighteen percent, something like that. There was an enormous difference, in other words, of the numbers of children who are involved in this study who are reading at essentially normal grade level, and again the preventative aspects, the reduction of frustration to those children and the reduction in negative self-concept, the reduction in their own feelings is what I think is the most important, because that's the way I tend to think, not as a clinician but as a person that manages government programs, the cost to that school system and society at large for those children reading at grade level versus not reading at grade level are just enormous and I think that all of you who are in this business understand that. So, I feel as though we need to begin those programs and not limit them to the educable retarded population, or to the learning disability population, but for all children. You can find comparable kinds of progress if not amelioration entirely in severely handicapped groups. For example, many children who we would have educated as deaf several years ago are now educated as partially hearing and even in integrated settings because of the intensive training of their parents to provide language and cognitive stimulation through the early years, use of amplification, preschool programming, etc.

So that's another of the Bureau's foci. Again, it's kind of related to this whole question of equal educational opportunity.

And another priority that we've pulled out is in the whole area of vocational-career education possibilities.

I think most of you know, as I do, that we've had a high concentration in special education programming in the elementary school years and then it kind of phases out. The kids are left to sink or swim as they get a little older. And at the same time, there are all kinds of good voc-ed projects around the country. Many of them are sponsored by special ed people, some sponsored by voc-ed, some involving voc-rehab in the kind of three-way deals which are showing remarkable success in placing young people in jobs. And we've had reports of projects, where eighty or ninety percent of the children were successfully placed. And that speaks very well for those projects.

What I've done here in kind of an anecdotal fashion is to trace for you some major foci of the Bureau's interest. One, on full service for all children. Two, on the analysis of where that full service objective breaks down, that is on the failure to provide for severely handicapped kids, on the failure to provide preschool services, and on the failure to provide effective vocational programs. Our services programs, our training programs, our research programs, our media programs each are trying to spend their dollars in such a way as to support these service objectives. They are trying to train teachers. I think we have ten projects, special projects under way in the severely handicapped or multiply handicapped area. The research division will focus dollars on the analysis of the problems of severely handicapped people. I expect, for example, we'll be putting into place some studies to trace what's happening to children who are deinstitutionalized. I'm terribly concerned that in our progress forward, in both main-streaming and deinstitutionalization, that we won't go far enough in checking the progress of these kids to make sure they succeed. We are all, I think, blinded a little bit by the glitter of getting those kids out of those settings and by getting kids into the mainstream, but we're not conscientiously following up to make sure that those programs are working. Philosophically, they are beautiful and I'm in favor of them; and on the other hand, I feel a deep sense of responsibility for trying to make sure that those programs work, and that the children do, in fact, prosper. So we've been conducting a big study which Marty Kaufmann has been managing for us, in cooperation with the Texas Education Agency, which we call PRIME. It is trying to measure the impact of main-streaming on Texas. We're going to go on into stage two, which we call IDEA, which will be a series of planning studies measuring what happens to kids, do they succeed, and what types of training do they really need. So that's where we are. There is one last thing I want to say to you, then I'd like to hear what you've got to say and to answer any questions, and that is that here in Washington this week there's a series on the 11:00 o'clock news on CBS in which the station is reporting on what happens to blind people and how they succeed in our society. And on ABC there's another series studying the effect of programming and labeling on kids. We've had the Washington Post and the Star News, which are our papers here, doing series on handicapped kids, columnists such as George Will, for example, generally identified as a conservative, writing very sensitive articles about the rights of autistic and severely emotionally disturbed children.

It struck me that what we have worked for is happening and I think all of us in this field should be tremendously encouraged. Society is beginning to come to terms, attitudinally, with the handicapped. And I think it's a very profound shift, part of the whole social revolution of the '60s and '70s that led us to be aware of the problems that blacks and other minority groups were facing in our society. Some of the sensitivity that we've begun to show for old people, the awareness is gradually growing in the area of handicapped as well. Whenever society begins to make such attitudinal shifts, it's always part of a cyclical process. We have legislation, which is one aspect of the government speaking in this area. We have Executive initiative, such as our promoting the concept of equal rights of handicapped children. We have judicial response, such as the court suits in Pennsylvania and the District of Columbia and a number of other states. This is a feedback process-- a continuous loop. It's hard to know which comes first. We know that the attitude, in part, creates the climate in which legislative and executive actions take place, and they in turn create additional public attitudes--witness the Brown court decision in 1954, which led to desegregation. We're into that kind of social climate and I think it has extraordinary significance for those of us in the field because we need to understand that our programs are not charity work. This is not something that we're doing here because we're all such good people. It is instead an enactment of a basic set of values and rights. We're dealing here with an intrinsic right of the child. My own feeling is that, as delightful as that is, it's also a little scary because it suggests the burden is on us for being responsible to these children. It's not going to be enough just to get them into school. I've made that a major focus of our activities. We want kids in programs, but the logical extension of that is how good are the programs. Do they work and are we being responsible? Are we reevaluating these children to make sure they are progressing? Are we specifically identifying our objectives for the children? Are we communicating with the parents about them? Do we all know what we are doing? And are we kind of keeping up-to-date?

We're not going to be perfect. You know that and I know that. I worked as a speech clinician with seriously handicapped kids and it was frustratingly slow work. I remember a client of mine who was a very bright guy and who had a tough problem, and he said to me one time, "Progress, if any, is infinitesimally small;" and it became kind of the keynote of my experiences as a therapist. And it helped me understand, you know, that you have to face where you are not doing well and not just talk about the cases that work out well for you. And I think we have that great sense of responsibility. It's been interesting to me that we hear a lot of talk about rights and I'm one of those who has been hammering on it for a couple of years now, and at the same time rights carry with them the other head of the coin which is responsibility. So, I think that is something that we face.

Our responsibility is not just, by the way, to do the best we can as professional people. But I think that those of us in the profession have a responsibility as citizens as well. Citizens who understand, because of

the nature of our work, some of the ways that handicapped people don't get a fair shake in our society. I'll bet you, and I can't see your faces, so I won't get the feedback except if you talk with me, but I'll bet you that if I were there now that some of you would nod to me when I say that you and I have watched children be placed in programs where they shouldn't be. We've seen children in special education facilities they shouldn't be in, substandard basements, old school buildings, churches, all kinds of places. We've seen youngsters in programs who should have been reevaluated and who weren't because we just didn't have the people to get around to it. In other words, we've participated as citizens in knowing the system was shortchanging the handicapped and we've said, "Well, we're doing the best we can, we're teaching and so forth and so on." But I wonder if we've carried a full citizen's responsibility, if we've used our teacher's organizations, if we've used our PTAs, if we've used our parent groups to keep these matters in the awareness of the school superintendent, to keep these matters in the awareness of the school board. Have we tended to think that our job ended when we went home from work and that we were doing the best we could in our classroom and that, you know, we weren't going to be able to rectify the larger evils in society? I think we've at times done that, and I don't think we can afford to do it.

One of the most profound and interesting things to me recently has been reading the statements of Alexander Solzhenitsyn. I don't know how many of you have had them available to you, but Washington Post has been carrying these statements. And the last statement that Solzhenitsyn wrote before being expelled from Russia was a statement that he wrote to his fellow intellectuals in the Soviet Union, and it was about lies. It was about two kinds of lies; the kinds of lies that he and others had tried to be forced into by the Soviet government—that is affirming things to be true they knew not to be true. And he went on to say there is enormous pressure on people to do that. You may have read this week another very brave writer in the Soviet Union who was given Gulag Archipelago to review and the government expected him to review it critically and he didn't review it totally critically. As a result the writer's union was about to expel him, and then he wrote an even more open attack on the system and defends himself in it. And I think what was happening there is that Solzhenitsyn's message to his people was really kind of getting through to them. They could not continue to say things that the state wanted them to say just to maintain their positions, and they needed also not to be quiet when certain evil conditions were present because that was another kind of lying—that was a lying by their silence—suggesting things were right when they knew them not to be right.

That's a heady kind of a moral challenge that Solzhenitsyn gave those people, particularly in a society which is so repressive and in which free speech is not really encouraged by any means. But we have even less excuse to do that in our society than they have in the Soviet Union. And I'm saying to you that I think in this year of rights, this year when we talk to each other about the rights of handicapped children, that that means we've got to not only do the best we can as profession-

als, but we've got to carry an added weight of responsibility as citizens to speak out about the lies in our own system.

Judy: Thank you, Dr. Martin. I think you can tell why he's not only Who's Who in America, but Who's Who in Special Education. I think that we can take time for just a few questions if any of you have them, would you come forward to one side of the room. Feel free, they don't have to be weighty or, you know, big important ones. If there's anything you would like to talk to Dr. Martin about or with, please commence.

(Question) Ed, in as much as you couldn't be here because you've been meeting with the problems on Capitol Hill, can you tell us what the current status of significant legislation for the handicapped is?

Dr. Martin: Sure.

(Question) Particularly the Brademas and Williams bills.

Dr. Martin: Okay. Well, I'm going to start with the immediate reality first, and then maybe move onto—what, future reality? Okay? The Education of the Handicapped Act also expired last year and it's in the kind of year's grace that federal education programs get. It has now been approved for extension by the House Education and Labor Committee as part of what's known as HR-69, the Elementary and Secondary Education Act Extension. Now, the gist of that legislation is that the current programs of education for the handicapped with which we are now familiar, the grants to the states, the teacher training, the research, the early childhood, the learning disabilities, services for the deaf and so forth, all those programs will be extended. The House has agreed to that. The Senate has already agreed to very similar packages, in fact passed S-896, the Randolph Bill. However, because of the fact that the House included the Education of the Handicapped Act in the Elementary and Secondary Education Act, the Senate will, this week probably or next week, repackage the Education of the Handicapped Act within their version of ESEA. This is a very good and, I think, forward step. The Administration is probably going to submit a modification of the Education of the Handicap Act to the Congress shortly and the timing is such that, I think it won't pass this year, although it may get studied. The new bill, as we would propose it from within HEW, would not be radically different than EHA. It would be packaged to some extent in smaller number of parts and there would be some interesting changes. For example, the learning disability youngsters would be included under the definition of handicapped, rather than in a separate definition. Our present program for deaf and blind children would be expanded to include all severely handicapped children. That's about the major changes in it. So, we think it might be a little bit more streamlined approach and we're interested in that change for the severely handicapped. I think probably those kinds of proposals will be considered by the Congress over

the next year or so and I wouldn't be surprised if they were adopted in part or entirety.

Now, one of the major changes in House and Senate Education of the Handicapped Act that has been receiving a good bit of attention here, naturally, deals with the Bureau itself. In both bills the Bureau will be extended and strengthened, and the reporting relationship to the Commissioner will be clarified. In recent years the Bureau has reported to a deputy commissioner and under the Bills now and under the Office of Education's plan, there will be a change in the Bureau's status. It will be directed by a deputy commissioner and it will report to the Commissioner directly. In addition, there will be some additional positions authorized and I think it's a very profound and important change. I'm glad the Commissioner has decided to do this and I think it's a good idea for the Congress to clarify its interest in that direction as well. I think my experience has clearly been that a strong administrative unit is still necessary if you're going to have the advocacy for handicapped children. That's necessary. I would hope that the states would take a look at the relationship between the Bureau of Education for the Handicapped and the Commissioner and see whether or not such a model might not be useful within state agencies as well.

Now, you mentioned HR-70 and Senate Bill 6, the key sponsors Brademas on the House side, and Williams on the Senate side. This is a Bill that all of you there might not be familiar with, but basically it proposes a very profound change in federal education policy—where the federal government would begin to support, at a very high level, approximately seventy-five percent of the excess costs of special education. So, what this would mean is—if the costs in Utah are \$2,000 for a handicapped child on the average and the average non-handicapped child would cost \$1,000—the federal government would pay three-quarters of the difference, or \$750 a child. Now, if you take \$750 a child and you multiply that by six million handicapped children of school age, not counting preschoolers, then you are talking about between four and five billion dollars. And I think the prospects of it passing in that magnitude are slim and none. And the reason for that is the total education budget for the federal government is about five or six billion dollars now. However, those Bills are very, very powerful conceptually, and they are, I think, very valuable philosophically because they do two things which are useful. First, they tie support to an individual child. They focus attention on that child. And some of the other characteristics of the Bill would encourage individual programming for a child. The federal law now in the Education of the Handicapped Act is not so sharply focused. The 313 law is partially focused in that direction—that is, a per child entitlement. I think the principle of having per child entitlements, or focus on individual children for program purposes is a very good posture, if you can do it. The second advantage is that the bills recognize the problems in financing that "full services" will entail, and they suggest a federal role on that basis.

Now, we have not had a federal role tied to helping with the costs of special education. The federal role has been a catalytic-demonstration role—beginning programs with seed money, not a "we're going to help pay the costs of this total program." And that's true across all education programs. The federal share of education is only seven or eight percent, the rest is state and local. So, there's a real question that's posed by these Bills that needs to be answered, and that is, should the federal government play a general support role in education of the handicapped? Is this an area, in other words, where the federal government should be a partner? If so, why? Why should it be here as opposed to some other education areas? Now, one may make the case that the federal government is quite a partner in the area of compensatory education, Title I, which will reach 1.8 billion this year. The federal government is also a partner in higher education area in a fairly significant way. A comparable opportunity has been granted to disadvantaged youngsters including individual grants and student loans in the higher education area. So it's not beyond the realm of possibility, that the Congress and/or the President might decide that there was a special need, a special situation that required federal remedy in the area of education to the handicapped. So, I think my personal position is that the Brademas and Williams bills are raising an issue that needs very serious policy study: That is, should the federal role become a service connected role in relation to helping the states support education for handicapped children? What my guess is, is that the specific proposals of these bills and the magnitude of the funding involved will not actually come about in the near future—but there might be some other alternatives, some modifications of these proposals which could still carry forward, let's say, some federal support role on a per child basis.

Thank you, Dr. Martin. Are there any other questions? None at this point? All right. Thank you and thank you, Dr. Martin.

Dr. Martin: Okay. Thanks a lot.

KEYNOTE ADDRESS ON THURSDAY MORNING

FRED J. KRAUSE

Thank you, Bob. In coming here to Salt Lake, I recalled visiting the many beautiful churches, the tabernacle and other sights of interest in your city. This brought to my attention a biblical story of a shopkeeper who was in serious difficulty financially, and he went to a money lender. This money lender had told him it would be no problem in borrowing the money he needed for his business enterprises, but he had a time limit in which to pay it back. Understanding these conditions, the storekeeper borrowed the money. However, after the length of time had passed—probably then too they had various recessions and problems in their economy—the storekeeper could not pay back the amount. The old money lender said, "Well, I have a possible solution. The solution is that you have a very lovely, beautiful young daughter. I will take her instead of the money." The storekeeper, of course, balked at this, but realized that he was in a very difficult position. The money lender said, "Well, we'll make it a little more of a sporting proposition. I will take a bag and take two stones from the pebbled pavement there, a black and a white, put them into the bag and she may pull a stone out; and if she reaches in and pulls out a black stone, she will come with me and your money problems are over. However, if she pulls out a white stone, then, of course, just the opposite." So the daughter had no voice in this matter. And as the very sly, ugly money lender reached down, she saw him palm only two black stones, which went into the bag. No one else had witnessed this.

How many times in our society today have we, too, been witnesses to the various types of problems and issues that confront the severely multiply handicapped, the handicapped or blind or deaf, certainly those which I am personally concerned with, on our President's Committee on Mental Retardation. We've witnessed many particular acts which we believe are not responsible on the part of the leadership—by those in the legislature or by those in various administrative positions throughout government; or certainly, too, the volunteers and others who have been apathetic to the developments and the action on the part of the severely mentally retarded. Certainly, there's been public attention focused on the deplorable conditions which exist in a number of the state and private institutions.

We have feature newspaper articles such as one right now in the Washington Post about the blind. And during these temporary periods of community awakening, concerns arise and certainly sometimes additional funds may be temporarily appropriated. But after the calm, we go back to being apathetic. We have witnessed, of course, in the public institutions the growth, that has taken place in overcrowding, in low levels of funding, and in other circumstances that have left many of these institutions providing only dehumanizing systems. We find, too, that while we want to, we cannot always meet these problems, because, again, of the apathy or the lack of full commitment. Compromise and compromise has been the watchword. We have been somewhat politically wise to these issues. We've tried to develop better systems. We heard Paul Thompson yesterday speak of the 313 programs. Again, Ed Martin this morning, about some of the advancements that have taken place in these areas.

But often they are just tokens.

Out of the next fiscal year budgets, we hear promises of what can occur if we are to economize in one or the other areas. The pressure groups from various agencies begin to rise for their own particular slice of the pie. There is then, too often, the retreat from the real commitment, to again asking that we wait another year.

We talk about our public institutions—have I mentioned that there are over 200,000 mentally retarded today residing in these public institutions, many of them severely multiply handicapped? We spent about one and one-half billion dollars last year in care and services in these institutions. Just like the storekeeper, we have not been making a fair return for our investment. You can merely visit many of these institutions and find they are basically custodial. However, through some projects of hospital improvement, programs of innovation and creativity on the part of certain staff, we do see islands of excellence. In fact, this was the report of the President's Committee for 1972, called "The Islands of Excellence." But as one congressman, Clair Burgener, who was a member of our committee, remarked, "Yet it is in the sea of mediocrity."

We are expending other investments into the community service areas—almost a countless number of dollars, by local, state and federal officials. They have been attempting to find alternative services. Many of our community service groups, I think well understand the needs for these alternatives, have been looking for standards, for ways in which to measure the results of their programs. As Ed said in his remarks from Washington, while we are putting money into these areas, we have little quality control. Yet these experiences, these experiments in a sense, are all producing in some measure the islands of excellence.

Oh yes, let me return to the Perils of Pauline as she witnessed the money lender putting the two black stones into the bag. She was asked then to reach into the bag and to pull out a stone. She knew that she had a stacked deck. But as she reached in, she took out a stone and, before anyone could see it, she quite accidentally, of course, dropped the stone onto the pebbled street. She remarked that she was very sorry she could not have shown them the stone, but there should not be any worry. They could look in and see that if there was only a black stone remaining, that she must have dropped the white stone. And I think in this regard we, too, have to be fast at hand. We have to be creative, quick thinking, innovative. As I sat last night and listened to some of the remarks in the various work groups, and as I heard the comments over coffee, there are many of you who are coming here with great innovative ideas.

I want to congratulate those who created and have implemented this conference. A lot of forethought went into it. We are beginning to look at these issues that Vance Engleman pointed out, and try to highlight ways in which we can reorientate our thinking to require us to give more consideration and effort to redefinition of our state's and certainly on our part,

our country's responsibilities. As public officials, as administrators, as teachers, as parents, we all must understand that the severely handicapped can be helped. A model that the National Association of Retarded Citizens has used for many years now, and I think very effectively, is to point out that they have not only a right to education but this is their constitutional privilege. This positive thinking will possibly overcome what I explained earlier—the apathy that rests in many of the states today.

Like the young lady, many of our volunteers and professional leaders have not only witnessed an act, but have taken specific action. Their quick thinking has caused a departure from the dehumanizing custodial care for new approaches, new ways, systems, alternatives to institutions, to community services, ways to reform some of our institutional programs, a variety of decentralized residential services. You'll hear more from Francis Lynch, who I know, from his vantage point as Chief of Developmental Disabilities, will point out some of the real advances that have been taking place through this more omnibus approach to serving the severely handicapped, those who are mentally retarded, cerebral palsied, epileptic, and have other neurological handicaps.

We are beginning to recognize, too, the human and civil rights, by not only court action on the part of the various consumer groups in the state, but also by the advocates in Washington, D.C. Yes, I consider the President's Committee on Mental Retardation a national advocacy group. We are not bound by unnecessary operational guidelines, but we are directed by the President, by an executive order which sets forth our mission to provide to the President and to the nation the status of our services for the mentally retarded. The reason I came here, more than the fact of just having an opportunity to speak to you, was to learn from you about the action in this four-state region. What's the status of your programs? What can I report to Washington to those 21 citizen members of our committee, who in their own geographical areas are strong advocates in the same belief?

We also have as our mission to provide dissemination of information, not only to the professionals in the field but to many other public groups that have had little contact, little awareness of what is happening, and in a sense to bring about a catalytic development between the various professional groups. We try to bring recognition also of the principles we are all working toward. It would be a normalization principle which refers to allowing severely handicapped to obtain an existence as close to the normal way of life as possible. If any of you have visited some of the public institutions and said, well this is not following normalization because you saw in one of the cottages a young boy running naked through the corridors, I think today maybe it is a little more normal, since he, too, is keeping up with the pattern of social life. We heard comments in some of our groups about the zero reject policy that Dr. Helsel spoke of yesterday. We hope this is being adopted, is being pursued as it is in Pennsylvania. Dr. Sherr and others remarked about the importance of identifying, of bringing some early intervention

and, of course, trying to provide whatever educational opportunities our system provides today.

PCMR has also, then, the mission of working with the various federal agencies. There are untapped resources not only in HEW, but in the Departments of Housing, Transportation, in Commerce, which has provided manpower programs and construction funds for various minority group programs through Equal Opportunity. Certainly in the Department of Labor. One of the largest grants I think NARC presently has is on-the-job training which comes from that group.

Now you may say, well, that's fine for the moderately or mildly handicapped, but what about the severely, multiply handicapped? Well, there are projects that are being funded. Very many of them that probably you need to know about because they can affect your service areas. We do have publications that give us some indication, some evaluation of these programs. If you care to write to the President's Committee on Mental Retardation, Washington, D.C., I will try to provide you with a kit of these sources of material that can give you some better ideas of assistance programs for other departments. You may be surprised to know that the Department of Defense, through its various military bases, not only here in our country but throughout the world, has a big investment in programs for the severely mentally and physically handicapped. I had the opportunity of visiting some of the overseas bases and saw classes for the severely mentally retarded. The Defense Department realizes they are confronted with some of the same problems you are. Often need is there, sometimes the facility is not totally adequate, but they are very proud of their dedicated and well-qualified staff. Possibly some of you in special education have been in the special education services through the overseas schools and branches.

I'm only bringing these to your attention because I think you have to break out of your yoke, because here, as I see today, are principally those in the educational disciplines. How many of you here in the audience are from the medical field? I see one hand, two. How many are from occupational therapy? Physical therapy? Just a few. I, of course, realize, as you do, that there's a big involvement here in various neurological problems and the need for early intervention, through physical therapy and occupational therapy services. As our committee toured the University of Kansas Medical and Research Branch in Lawrence, we were very impressed with some of the early intervention programs that Dr. Dick Chiefelbush and others are performing there through the occupational therapy and physical therapy services.

I have talked to the president of the American Academy of Pediatrics, particularly the chairman at the time of their sub-committee on mental retardation, Dr. Robert Kugel, a former member of our committee. And he remarked that one of the biggest problems the pediatrician is faced with today is communication with the teachers. I couldn't, as a special educator myself,

first grasp what he was saying or fully understand this, because I felt I was in teaching, in communication with the medical profession, but I had to admit I didn't think they were around very often to be of help. But I feel that there have been many breakthroughs on the part of the medical profession, the psychiatrists, the pediatricians, who want to work more closely today with the other important disciplines and, particularly, with you, as the educators.

Now, the President's Committee has attempted to bring about this liaison. With your help we can do more. We find, too, that we have tried to establish some national goals. One of them has been in the area of prevention. And there, of course, we work closely with the various medical organizations and agencies through the National Institute of Health in Washington, the National Institute of Child Health and Human Development and many other branches. We find that we can, if we apply the existing knowledge we have in the medical and scientific field, reduce possibly by 50% the incidence of mental retardation.

We find that one of our other goals which has received a fair amount of attention by the country—and we're very pleased with the amount of interest it has generated through Washington—is for deinstitutionalization.

We set by this goal that of the 200,000 mentally retarded in our institutions, at least one-third could be moved into the community. The superintendents themselves have been surveyed. They remark, after analyzing their population, that as much as 54% of their current institutional population could be moved into community service if—if—these alternative, these community programs are available. As we pass many of our programs for improvement of educational funding, we do find a great reduction in the waiting list of the institutions. Of course, if we can prevent the institutionalization in the first place, our job is considerably easier, because once someone has resided in these institutions, the process is considerably more difficult. We also find that in this process, we have to try to find many untapped resources. I was going to relate to several case studies on those in the institutions, but because time is running late and I know you've had a long day yesterday and many hours ahead of you, I'm going to refrain from going into detail of case studies.

The point is that on many of the issues and questions that confront the severely mentally retarded—and in spite of the obstacles—we are able to make some important breakthroughs. To remove the inter-barriers, to provide them some of the freedoms and opportunities through good team approaches, good prescription teaching and many other advancements, we've been able to make in early intervention.

Ed Martin remarked about several studies that have given us some important data on what we can save if we bring about early intervention. We did a study. I should say we've done several pieces of work, in the area of what we can find from early intervention programs, such as Rehabilitation of Families at Risk for Mental Retardation, known as the Milwaukee Project.

This project deals with the young child, preschool age, and parents in overall rehabilitation of the family. Lou Brown of Wisconsin is intimately familiar with the work there. I'm sure too we can cite many other example. But we've felt we really had to pull this together ourselves, so this May we're holding a national conference on some of the early intervention programs in Chapel Hill at the University of North Carolina. We hope the results of that work group will be of some assistance to you in knowing what early intervention services are taking place, what the federal resources are, and how we are being able to make some important developments in that field.

Our goal for the severely handicapped should be to design programs and services to help each one to develop as a person, to achieve the highest level of independence possible, according to his capabilities. Our report for 1973, which is at the printer at this time, is striking hard at that theme. To achieve the highest level of independence possible according to the child's capabilities. To accomplish this we have, of course, asked many of the federal agencies to bring forth new means by which they can finance some of the services and programs. And in the Office of Human Development—many of you may not be familiar with this newly created agency in government—is the Office of Child Development, a children's bureau and several other services are combined there. It has the financial resource through Head Start, which as you know 10% of the funding programming there is to go to the handicapped, early age. We can do a great deal more, and that program is being advanced by some thirty-nine million dollars. Other areas of Office of Child Development are equally being advanced about thirty-nine million dollars. So you have here close to an eighty-million dollar influx of new money, which can go toward many of the early service programs that you may want to take advantage of.

How many of you are working with the Denver or Seattle offices? I hope you are more and more realizing that through federal decentralization from Washington, we are trying to create a means by which more of the services are local and are more accessible to you. Dr. Garfield, who I spoke to just day before yesterday in Denver, asked me to stress this point. As several of you know, he is very concerned with the Rocky Mountain area since he has resided here for many years. And he feels that the Denver Regional Office can be of great help and assistance if you reach out for its aid. And I believe he told me he was going to be speaking, if I'm correct, at the Wyoming convention of the ARC, and he hopes that many other invitations for not only him but members of his regional staff will be forthcoming.

They'd like to tell you about some of the other developments throughout the country since we've been trying to disseminate information to them. Since I had several years' experience in California, I can't help but remark about the delivery system in that state. Through regional diagnostic and counseling service centers today, they are able to reach the families; to provide not only the diagnosis, but also the counseling with the parent, and a service component which pro-

vides for purchasing services. It's not perfect. It has many flaws and problems, but it has, at least in the state of California, eliminated in three years the waiting list which was in excess of 3,500. It has further eliminated a number of those who were in the institution—who were principally residing there with no services or program—to the alternatives that were being made available by this purchasing of services contract arrangement for community programs. At the same time it identified many of the gaps in services, and one of the major gaps for the severely handicapped was what then they were calling child care or day care. We found that this terminology left a lot to be desired, particularly in the minds of the legislators, less sophisticated as to what the programs and services real content was. And in one brief moment, several of us put our heads together and said we see the problem here, as we are confronted with it in terms of this finance committee: they resent the term day care, they think of it as baby sitting. Let's go back in there and tell them we're talking about child development—developmental centers for these severely handicapped. To remove them from the institution or to prevent their institutionalization. I thought we were appearing in front of a totally different group after that recess. As we remarked we were not talking about baby sitting, we were not just talking about day care to allow mothers to go to the beauty parlor or shopping, but we were really talking about the child's needs, the development of services. And immediately funds became more readily available.

Today the system of child development centers for the severely handicapped are in every school district in the state of California. And by 1977, in a bill signed I think last week by Governor Reagan, it will become mandatory, it will be a state law, that all school districts are to provide, from the age of three, I believe there's no top cut-off, but if there is it is somewhere around twenty-four years of age. The fact is that this is an important program and we should, in time, drop the word "child" and consider it as developmental centers for the severely handicapped—in terms of these programs as integrated with the school system, not part of public health, but with the education discipline with which it rightly belongs, with the support of the social work, of the PT, the OT and, of course, the physician.

As we look at some of these issues, let's set our national agenda for these questions and issues. We, who have been looking at this only from the Washington perspective, find that there are many internal barriers that I've already remarked about that we can overcome. We can possibly develop more services, but external barriers also stand in the way of progress. They will fall when certain goals are realized. These goals and issues are when every state gives priority to community based services, when every community meets the quality standards set forth in both its community and residential services by the Accreditation Council for Facilities for the Mentally Retarded, which have every application, as Dr. Helsel can tell you, for other severely handicapped groups. And every community identifies one official or agency as being ultimately responsible for retarded or severely handicapped individuals in the care of that community, and for assuring that a broad spectrum of quality services are available to them.

As long as we leave this out in the so-called never-never land as to who is really identified as responsible, it's going to be left in that kind of a maze. Let's try to identify, then, what official or what agency has that principal responsibility for target areas of lead agency involvement. And when every legal right victory in the court is made meaningful in the lives of every severely handicapped child and adult, I think as you have discussed here in some of your work groups, litigation is not the first line, it's the last thing you should do. But when you do, make sure you have the facts and you've tried every other alternative.

This past week, the federal government, after trying several other ways, has finally taken its civil rights issue to the state of Maryland for the continuation of dehumanizing programs there in the Rosewood facility. I know from Mr. Stan Pottinger, Assistant Attorney General, Department of Justice, Civil Rights Division, he plans, with the cooperation of many professionals, consumer and advocate groups, to file other suits if no other course of action is open to them.

Further, that every state enter into a long-range program to train and enlighten its administrators and professionals of all programs serving severely handicapped persons. And when every mentally retarded person achieves the right to choose a place to live, without discrimination from zoning barriers and personal rejections, then we'll be able to overcome some of these external barriers. And I don't believe the word "constraint" as we've been using it, as I define it, is a way in which we're going to be constantly bound. These are obstacles, these are barriers, but they can be overcome. They are not restraints that can't be broken. They are only obstacles that can be broken if we really work toward our very creative and innovative ways to accomplish it.

And that every handicapped individual can be hired or found with some vocational or economic potential to do the work and not be discriminated against because of his IQ or other known handicapping conditions.

Now we don't believe that the President's Committee by any measure can just recite these things and they are going to be ultimately moved toward action and accomplishment. But we are trying, through preparing a monograph on planning community services for the mentally retarded and severely handicapped, to point out ways in which we can overcome this. Dr. Gunnas Dybwad and many other colleagues of his throughout the country are working with the President's Committee on that project right at this time. We are trying to update a monograph which had been a best seller of ours in a way, and that was changing patterns in residential services for the mentally retarded, which was first done by Dr. Kugel, Dr. Wolfensberger, and others on clearly describing the normalization principle. We're trying to reach the public through the various media, through TV and radio and newspaper articles and through our own advertisement as to what are the rights of the handicapped. April is being proclaimed in many states and throughout the nation as the month in which we are trying to focus on the legal rights of the mentally retarded and those of other handicaps.

We are launching an effort jointly with architects to deal with the building code questions, the barriers, the zoning and other questions that have prevented their accessibility to programs and, of course, their ability to live where they choose. And travel where they choose, likewise. We are editing other publications and I won't for time go into great detail, but we often need your help and assistance in trying to see ways in which we can be more meaningful to your situations.

We have talked a little bit here, but I would like to re-emphasize the importance of technology today. Paul yesterday talked about the telecommunications. In your area you are a little more enriched with that opportunity than other parts of the country. If you are familiar at all with the project out of Denver, which Dr. Lou Bransford is working on, it is a technology in which we are, through the various telecommunication satellite systems, able to create a means by which we cannot only reach into many of the rural areas of our four states (in fact there are eleven states engaged in this project, principally aimed at some of the rural areas where Chicanos, Indians and our various other rural population reside today), but to find within some thirty-six centers ways of two-way communication on health services, educational services—and I presume your imaginations could go on to parent education and other services—and communicate to the main station and center in Denver, right back again to this particular regional center for this communication hook-up. It is available, it is existing. In Dr. Bransford's way let's not recreate the wheel. Let's use our systems that are already available. There are many means by which we can reach them—literally hundreds of thousands of people—who have been previously isolated because of their distance from the main sources of the educational discipline here in Salt Lake and other cities.

We have, of course, miles to go. It's a long road, many new technological and innovative areas. Let's be witnesses also to the progress. As Michelangelo once was asked, as he stood in front of a large piece of marble, "What do you plan?" His answer was, "I plan to release the angel captured in this stone." And I think you here today have also that opportunity as you are confronted with some pretty big boulders yourself. Begin to chip away and to carve out what is captured inside and that is many severely handicapped who are not released. Many are the bondages they face. They are your challenge, and you, as professionals, have this responsibility.

KEYNOTE ADDRESS ON FRIDAY MORNING

FRANCIS LYNCH

Thank you, madam chairlady. I was delighted with a remark that Judy passed as I came in. Undoubtedly to make me feel more relaxed and more at ease, she said, "It's so nice to have people from Washington come and recognize that they are really human beings, they really do understand some of the problems that are going on." Now, that was immediately after being rather in the doldrums on entering the room this morning, seeing the white chart over there. The white chart identifies one of the problems and one of the barriers that you all face in carrying your work—the bureaucracy.

Now, I hope my remarks on some of the work here will indicate that the bureaucracy is part of the solution. It's not only part of identifying the problem or, indeed, part of the problem itself.

Discrimination against the handicapped being physically and socially unacceptable has always existed. Despite the progress in the last few years towards the elimination of some of the stigmas associated with these individuals, we still have many unresolved issues as we attempt to integrate other persons into society and, unthinkingly, expect them to accept our ways.

As you know, we have been operating the program that I'm responsible for—I'm the administrator of the federal service that is Developmental Disabilities legislation—since October of 1970. And until June 30, 1973, was the predicted life of the program at that time. In the last year, under the umbrella Public Health Service Act, and until June 30th of this year, we will have life. We are now awaiting answers from the crystal ball, watching the Congress, watching the constituency to see what the future holds for the developmentally disabled in our program.

And this waiting period I mention launches me immediately into the problems and issues which we face in attempting to find adequate and appropriate services for the developmentally disabled in our program—more so when we consider the thing that we are concerned with is continuity of service as an issue. Our program authorized for three years had, in its inception, a forward looking thrust to cut across categorical lines, to let the states run their own show, and to get action at the national level. It is a catalytic program, bringing together a larger population having common needs, yet differing in their categorical classifications. The main thrust being made is to bring about interaction between and among this target population and a comprehensive group of authorized services for the target group's well being.

As in any interaction, it must be the play between two or more factors that's important. Such was the case under the Developmental Disabilities program. On the one hand, we had a selected group, disabled by conditions of neurological origin, whose handicaps might be one or many and in varying degrees of severity. And on the other hand, an array of sixteen basic services which must be put in place both latitudinally and longitudinally for a person's entire lifetime. We wish to bring these services to the developmentally disabled in an economical, effective and in as appropriate a manner as possible. And although we did get off to

a slow start in financing and having boards created and appointed and developing a new formula grant approach in lieu of a project grant approach, we believe that the services accomplished in the last three years are worth continuing. That, of course, takes additional monies and additional manpower and legislative support and, most importantly, consumer and consumer representative involvement.

So let me tell you some of the problems uncovered, the issues and what we have to look forward to. At once we were embroiled in issues over definitions of terms, of stipulations over acceptance on resource programs. There are nine agencies in the federal government—particularly in the Health, Education and Welfare—concerned with the developmentally disabled. And in the private sector there are many more. Each agency defines its terms, publishes regulations and guidelines. The target population of private agencies is determined by their boards of directors. And so here is conflict already. One agency will accept individuals from 18 years of age on, another agency serves up to age 26, the next agency says ambulatory only, and the next agency has such a heavy waiting list it refuses to accept the more severe cases since the latter's problems are usually time consuming.

The severely disabled defined as acceptable for service by one agency may be excluded for service by another agency because of its interpretation of severe disability. So one issue arising among the agencies and which may be of interest to you, is who are the severely multiply handicapped? We, working on developmental disabilities regulations and guidelines, are in agreement with PL 91-517 definition. Other federal agencies must be in line with their funding authorities. Thus, various federal regulations and guidelines are major inhibitors of joint projects when funding is derived from several sources. Also, private agencies must be in line with their funding authorities and their obligations.

Another constraint to coordination among service agencies is the reluctance of agencies to relinquish control of their separate delivery services. Also, another constraint which should be mentioned is that about 85% of HEW's budget is in terms of uncontrollable expenditure, welfare, rehabilitation, medical services for the poor. Thus, we must learn to set priorities, to choose, to make common goals truly common, to find common definitions. Common or at least flexible regulations would lessen the red tape and help service providers break down the barriers to service integration. More work needs to be done on joint plans, the comingling of funds, and joint operations which cut across program lines. There can be no hope of building service networks without gaps or overlaps unless we establish clear definitions of authority, responsibility, and territory.

Now in terms of services, let's look at some of the services for which provision was made under the Developmental Disability Act. Education, which you

are most familiar with—we still have the situation in the United States where entire school systems violate existing laws by excluding handicapped children. According to Senator Harrison Williams' report, one million handicapped children are excluded entirely from public school systems in the United States. This disaster is due in part to state laws and various interpretations of the laws by local school systems. A Supreme Court decision in Wisconsin affirms the right of local school systems to exclude a student provided a free public education is provided by another means. Even where the laws are specific and clearly understood, local school systems, overcrowded, under-staffed, probably using double shifts, avert the gaps from the child who is going to need special attention, special transportation and so forth. An increasing number of slighted cases have been brought to court and have gained national attention.

Formerly, under Mental Retardation Law 88-164, protests were made by the advocates. But now we have a group of multi-handicapped, some of whom can speak for their own group. But the group that was starting to be vocal is scattered and it is politically weak.

Transportation—there's another item. Wheelchair cases and other severely disabled individuals may not be able to travel via bus, train, rail or subway. Legislation on some attempts to ameliorate this problem and the rights of the handicapped to have and use—particularly in Washington, D.C., the development of their new Metro-Transit System, that I'm referring to—to have use of intra- and interstate transportation facilities. But even when established by law, existing action has not taken place or has been ineffective. Special equipment, such as many of the multi-handicapped require, is expensive and may require extensive renovation or replacement of existing equipment. With transportation companies plagued by a fuel crisis and the subway and buses already offering standing room only, it may be some time before the severely handicapped achieve their full rights to the use of transportation facilities.

In terms of architecture, it is impossible still for many of the multi-handicapped to have access to most buildings, hampered and barred as they are by stairways and curbs, the lack of elevators.

One of the prime offenders is the federal government system in Washington, D.C. It's impossible for a handicapped person who is confined to a wheelchair to mount the steps of the Lincoln Memorial. Still, at this date, Federal laws now require all new federal and federally financially assisted facilities designed for use by the public to be readily accessible. This law does not provide modifications for existing structures, however, other than those altered for federal use or with federal funding.

State laws may vary on accessibility requirements. There is much to be done on accessibility requirements as a universe. Although we have noticed ramps, lowered water fountains, widened doors in elevators and so forth in public buildings, existing private

structures have not had to conform to accessibility requirements. Yet many a severely handicapped person would like to get access to services in a private building. If the severely handicapped individual is denied physical access to services for his needs, it might be possible to remove the interference to his constitutional rights by court action. Although court action causes are becoming more frequent, I think you will agree with me that it is going to be a slow process for the severely handicapped individuals in obtaining their constitutional rights by depending on legal action only. For one thing, they cannot always speak for themselves. When and if they do, they do not present a political coalition. Cases are resolved one-by-one at a time.

Moving into the area of employment, in terms of the federal and the private and the sheltered, proposed amendments in the federal area to the Civil Rights Act of 1964 would have prohibited discrimination against the handicapped in federal programs as well as in private employment. But no action was taken on these amendments. There is a federal employment program for the handicapped and the government sponsors an Employ The Handicapped Week. But according again to Senator Williams' report, only about two-thirds of the severely handicapped in one study were able, after training, to obtain employment. Private industry is indeed remiss in employing the handicapped, fearful that its insurance rates and workman's compensation rates will rise.

Not the least barrier to employment is the prejudice of the employer. One of the groups most discriminated against is the epileptic. We are learning from studies now being done with funding from my agency that it is possible to have better seizure control by measuring the adequacy and activity of the anti-convulsant drugs in the blood. This is a unique and I think a landmark program that benefits not only the mildly handicapped epileptic who can work, who can maintain himself in the community, but it is also an extremely useful tool for those who are severely handicapped by or with seizures who cannot respond to check and see whether they are being overdosed or whether seizure medication is being used as a constraint. The implication of wider use of these techniques is that more epileptic persons will have a greater chance of returning to community living and have increased opportunities for employment.

Now in terms of the multiply handicapped in the community, for the multiply handicapped who return to the community from an institution or who have remained in the community—who is the one person to whom they are responsible and who assumes responsibility for their follow-along? Is it a staff member of the residential institution from which they were recently discharged and with whom they have infrequent or sporadic contact? Is it the welfare department—suppose they are not on welfare? Is it the boarding home supervisor? Should it be any of these or a special advocate or an agency in the community? It was de Toqueville who wrote, many years ago, "The evil which was suffered patiently as inevitable seems unendurable as soon as the idea of escaping from it crosses men's minds. All the abuses then removed

call attention to those that remain, and they now appear much more galling."

Although some of the problems were resolved, some of the issues were resolved, during the past four years we have worked in the area of developmental disabilities, we have become more sensitive, indeed, to those that remain. We know that legislation does not solve problems. People create them and people solve them. So what do we need to build on these accomplishments of the law in the coming years? We need a chain of cooperation, of both the private and the public sector at all governmental levels. We need, and have made, a start at interagency linkages across categorical lines with emphasis on the services rather than on the disability. We need more application of existing therapeutic measures and follow-along to lessen dependency, prevent regression, and make the severely handicapped, multiply handicapped more enjoyable and more employable. We need to recognize that although the Developmental Disabilities Act presents us with a new idea in the delivery of services --and we could spend years translating the blueprint into action--we feel we have demonstrated the work of such an approach and note that the Allied Services Act of 1974 is similarly structured.

We are dealing with a new philosophy--accept individuals on the basis of their ability, not their disability. The more severe his handicap, the more multiple his disability, the more frequently does the individual encounter prejudice and aversion in society. Thus, although we have made much progress in bettering the lives of these most disabled individuals, I see acceptance as the chief issue upon which we must concentrate.

The two principal bills in Congress concerning DD are Senate 3011, introduced by Senator Jack Javits on February 18, which amends the Public Health Service Act, the DD Act, and the Comprehensive Alcohol Act of 1970. Under this bill, the DD bill program would be extended for three years. Autism would be included and there would be an increasing emphasis on deinstitutionalization as a program objective.

The other bill, HR11511, introduced by Congressman Rogers earlier and on which hearings have been held, requests a two-year extension of the DD program. It is structured essentially the same as 91-517, the present authority.

One of the things that I heard in my sensitivity ear yesterday at this conference was--I got the feeling, I guess, that there has been much said about moral issues and moral judgments and about constraints and about barriers and about problems and less about solutions. Now, I as you have been around long enough to know that one of the more odious things that Washington-types do when they come out into the hinterlands and speak is feel impelled to leave you with an uplifting message. Recognizing that, I thought that perhaps as I was perceiving it, one theme was perhaps missing that I want to leave with you as a person rather than as a Washington bureaucrat. Unfortunately, I don't have my speech file with me. So I had to make a long distance call to the

Office of The Society for Crippled Children and Adults in Chicago, and call on my colleague Jane Shova and ask her if she would open her door and read to me what she has written there--something that has impressed me for some time. And the title is "Press On." And the theme is "Nothing in the world can take the place of perseverance. Talent will not. Nothing is more common than the unsuccessful people in this world. Genius will not. Unresolved genius is almost a proverb. Education will not. The world is full of educated derelicts. Persistence and determination alone is omnipotent."

Thank you.

THEMATIC STATEMENT FOR SYSTEMATIC DELIVERY SYSTEM

BY DR. RICHARD SHERR

Before I talk about providing a systematic delivery system, I would like to give you something of a context that you can relate our delivery system to—what has happened in Pennsylvania and what some of the preceding events were. Before I do that I'd like to ask a question of you, and that is how many of you know what we mean by "right to education"?

I think we've got some work to do and I hope by the time you leave at the end of the three days we will all know that. The reason I ask that question is that it's the kind of statement that we all think it means something to us, does mean something to us. But to parents, a right to education means many different things and to professionals, I'm finding as I talk with you here and as I talk around our state and around the country, it has a different connotation also. To parents a right to education may mean finding the right educational program after many years of not having any program available to them. Some parents see the right to education as a means to the kind of programs they want whether it is appropriate or not. Administrators may think of the right to education as simply putting the child into the school process without any consideration as to what is most appropriate and beneficial for the child. You, as concerned professionals, should think of the right to education concept as not only a program for a child, but the most appropriate, beneficial, meaningful program for that child. And I hope we can spend some time today and tomorrow and the next day developing what is that kind of program.

The above statement regarding the right to education without regard to degree or severity of conditions is probably a myth in the United States, despite the rapid increase in state departments and the rapid increase in litigations. It's a myth because we have not really defined what we mean by a right to education. Looking at the right to education in Pennsylvania, which has been widely acclaimed as a model and in some cases litigation follows very carefully right after the Pennsylvania model, we think it has many good aspects. Unfortunately, it only addresses itself to the mentally retarded. And as you heard this morning, there are other multi-handicapped individuals besides the mentally retarded. Despite the flaws, the fact that it addresses itself only to the mentally retarded, there are many good things in the Pennsylvania consent agreement. And I would like to review for you how one regional service unit became involved in a comprehensive delivery system for severely handicapped. It would be beneficial to sketch out some aspects of the legal and legislative features relative to the Commonwealth of Pennsylvania and the specific features of the agreement.

There were two major impacts of the Pennsylvania agreement. The first was that all children were to receive a free program of public education without regard to severity of retardation. Notice, I am saying retardation. All children, without regard to severity. The second aspect is that all children and parents are given the right to question the placement or nonplacement in a program through a due process procedure, which includes a formalized hearing with the hearing officer delivering recommendations. There's a lot of

impact to that because the hearing process really serves the family. These two procedures are very significant. However, to implement them, other significant aspects of the program were developed. Most significant of these was the fact that the federal court assigned masters who were professionals, in one case an attorney, to develop a process for the state whereby all the features of the right to education program must be delivered. This process was very complete and wide-reaching and was developed and implemented as part of the State Board of Education regulations.

What I'm saying was each school district couldn't go about, in their own way, delivering education to all children. They had to follow the process which was designed by professionals and an attorney and then accepted by the federal court. The Commonwealth of Pennsylvania was mandated, and the school districts also, to follow that process. So there was some uniformity of the programs.

Another significant feature of the consent agreement in addition to the process was the amount of effort expended by the state, in demonstrating to districts and regional service units how this could be done in terms of statewide in-service programs, publications, manuals. A great number of meetings, very much like this in terms of helping school districts implement these procedures.

In terms of describing to you how the systematic delivery system was developed in one area, I would have to give you something of an overview of our area. We're a two-county unit with twenty-two independent school districts that we function within, as a regional service unit providing most of the services—all of the services that they desire—and most of the services in special education. The districts have a great deal of autonomy and we act and work with them very carefully in developing procedures. We do not mandate to them nor we do not act with them in an autocratic way, but in a cooperative way and that's rather significant.

We serve about 100,000 school-age children in those two counties, and I mention that to you because it relates somewhat to the areas that you folks are trying to serve, either in multiple district arrangements or county arrangements, or in some cases state arrangements.

With that kind of context, I'd like to talk a little bit about the systematic delivery system. Before we do that, I hope that we are all talking about the same kind of child. As I talked to several people at the conference I heard them talking about a child that was somewhat different from the kind of child we're serving as our multiply handicapped child. I'm talking about children that do not have mobility, that come to us in a little van, strapped into a wheelchair, the wheelchair strapped into the van. And when they get into class they may have to lie on mats. I'm talking about children who do not have bowel and bladder control and cannot feed themselves and are not able in some cases to turn over on the mat. Now surely that's the most impaired of the children, but we have a

number of children of that type. That's what I'm talking about when I talk about the severely multi-handicapped child. That's the kind of person I'm going to be addressing.

The beginning phase of our development of our program was a very careful philosophical review within our intermediate unit as to what we wanted to do and how we wanted to go about it. We knew we had a federal court order that was upon us. We knew that state regulations had certain other mandates. We did not go off willy-nilly developing classes without some philosophical rationale, some philosophical basis to lead us as we developed a program. I think that's important. Otherwise, you might end up with a hodgepodge of services. So the beginning phases, which you can well do in this conference here, is to determine where you want to go and how you want to go.

The next step was a very careful review of the legal mandate and a very careful review of the newly organized state regulations, so that we were not in any way liable--liable in the eyes of families as we developed the services, but to make sure that we were in the context of the law and also the state regulations. We also searched that very carefully, so we would see what financial responsibilities the state would bear and what financial responsibilities we would bear. And that's an important consideration also.

It might well be that as you develop programs voluntarily, that you do not do that under a court order or by state regulations, you won't have that same problem. But as I look at the climate across the country, I suspect that many of the programs are going to be developed under court orders or under state regulations.

The third step that we took in developing a system was to work very carefully with our constituent school districts. We met with the twenty-two independent superintendents. We first hit them over the head with a lead pipe--the court order--to get their attention; then we threatened them that we would not defend them if they got into a court suit. We had their attention, we started developing cooperative arrangements in how this shall be done on the intermediate unit-wide basis. Most of our districts--all of our districts operate their own educable retarded classes. Intermediate units develop the trainable programs and we also develop the total program for the severely, multi-handicapped.

It was important that we work with those twenty-two school districts because even though we are funded by the state, they ultimately pay that bill because the state charges that back to them on per-pupil basis. Also we needed facilities in some cases and we needed the support of their administrative group.

After we had worked with the school districts, our next step was the search for children. That sounds rather strange because every state has some kind of law that you must maintain an annual census of children and so on. But you would be surprised when you look into it how loose that annual census was. It was also imperative that we search for children because the

court order said each intermediate unit school district in the state department shall seek and locate every child retarded or thought to be retarded and we wanted to comply with that to the letter of the law, so we searched very carefully. We did that in a variety of ways, covering a two-county area, two major cities, and twenty-two school districts. We covered a wide area, as you do also. And we couldn't, obviously, send staff out into the fields so we used the media newspaper advertising, we worked with the two television stations that serve most of our area in terms of TV spots, we approached all the civic clubs, had them make announcements at civic clubs, we engineered through our school districts that every school-age child took home a flyer, and the intent of that entire message was, do you know of a handicapped child, a retarded child, if so call this number. We had a full-time secretary who did nothing but handle the phone and keep the list of children.

It is interesting that most of the children who we learned about we already knew of or had in a program. We turned up about a dozen children that were in someone's attic or hidden away in some other part of the house, that we did not know before. I might say we were rather pleased that there weren't more children that we weren't already aware of, or serving.

After the location and identification phase it was important for us to know what skills these children had, what were their major deficits, what did they need. And we referred to that as the evaluation phase. To simply take a name and a suspected disability and place in a class was not reasonable, so we had to gear our total staff of psychologists that summer to evaluation of the children. Our psychologists still shudder at that experience, but it was necessary if we were going to develop an adequate program for the children. We also inserviced all the local district employed psychologists. We had a team of twenty psychologists that worked evaluating all the children whose names appeared whom we did not already know.

In the evaluation process, we had to have, we felt it essential we have some uniformity among the psychologists, so we used the state form which was a fourteen-page evaluation form. Now it's not significant that it's a fourteen-page form, as a matter of fact, it could be boiled down to fewer pages, but it is significant that we got the same information about each individual. That way we could start grouping for classes and so on.

After evaluation, the next step was placement. We looked at the array of classes that we had, trying to group the children to the best programming. The next major consideration was staffing. A lot of the children that we uncovered were children that were already involved in some type of program that was sponsored by an ARC Chapter or UCP Chapter or by the Department of Mental Health and Mental Retardation. We had to assume those children. In several cases of our staffing, we took the teachers already involved, even though they were not certified in the education system, as temporary employees until we saw what kind of skills they had and whether they could be the kind of professional we wanted. And

interestingly enough we turned over about fifty percent of that personnel by the middle of the year. Some of the people did not want to do what we wanted to do or they couldn't meet the certification.

Then after we selected staff we found that there were still great gaps in the kind of delivery in the classroom we needed, so we became involved in a very intensive in-service program. The teachers were a dedicated, committed group of professionals and they didn't mind giving us time in afternoons and early evening to work on the necessary skills that we felt they had to have.

The final phase of the program we delivered was the evaluation after that first year. We looked at what we did right and what we did wrong and tried to revise what we did the next year.

So much for the systematic delivery system. The final point I would make to you as you deliberate over the next three days is the kind of feelings and thoughts that you have in your head about serving the multiply handicapped children. We had some people that were very honest with us on our staff. They said to us, "I don't feel I can become intimately, deeply involved with the type of children we are dealing with. I'd like to be reassigned." We tried to honor that request. I think you have to search in your own mind—is this the kind of child you want to become involved with. Then acquire the skills to do the job.

That's a very cursory overview. If you are with us in the several remaining workshop sessions I'd like to dig as deep as we can into the several points that I mentioned to help you in the context of your own school administrative system to develop the same kind of program for your children. Thank you.

THEMATIC STATEMENT FOR IDENTIFICATION OF CONSTRAINTS ON GETTING CHILDREN SERVED BY DR. ALBERT BERKOWITZ

Last October when Vance called me on the phone and invited me to Utah, it seemed like it was terribly far off and I was about not to think about my charge then for the next three or four months. I hung up the phone and, of course, my compulsivity said, okay, get ready now. So in sort of a stage whisper I said, identify constraints to the delivery of services, hmmm. And my secretary popped up from the behind and she said, "That's not a problem, we've got all that in a neat little package." I turned around quickly in the chair and I thought, I've got it made. "Where is it, Jeanie, bring it, show me." And she said, "It's right in front of you," and she handed me my appointment book.

At the time I really appreciated the humor but I didn't really appreciate the insightfulness of that secretary. She's absolutely a wonderful girl and she is indeed the part author of this paper. I have already told you in my pre-conference message that with a very minimum of effort I was able to identify a dozen or so constraints. And about two weeks ago I decided that Jeanie's idea of looking in my appointment book and other appointment books was probably a much better way to describe some of those constraints. Especially the way bureaucrats spend their time. And so I sent a quick memo to the five chiefs in my office and asked them to send me their appointment books. And this is two weeks ago Monday morning and this--some of it--is copied out of their books, others were little discussions that I had with these five chiefs. I think you'll probably be able to recognize the constraints.

The first one that I looked at was the chief of developmental day care centers. Her morning activity was centered around a transportation problem. We in the Department of Mental Health run or operate developmental day care centers for school-age children that are excluded from public school programs because they are severely multiply handicapped. Many of these children are low intellectually functioning children and the day care center centers around being a core program more than an educational program. Hopefully, we are moving towards changing that a little bit.

This year we were fortunate in convincing the local school boards to pay for the transportation of our client to and from the developmental day care centers. And it seems as though we overlooked one important thing: school runs from September to June with three or four weeks of vacation in between. The developmental day care centers, as alternatives to institutionalization, run twelve months a year. A sizeable number of our clients cannot come to the program for many, many weeks of the year, simply because the local school system has not contracted with the local bus company to provide that kind of service. That's not resolved, by the way, so there's no happy ending to that one.

The chief of residential care had a telephone meeting with a legislator. I guess maybe this is the predecessor to the Martin Bell Telephone Conference. It seems as though this legislator has a constituent with a twenty-two-year-old daughter who has been living in one of our state schools for the mentally retarded her entire life. The staff at that school is determined that

she would be better off living in a small community residence. That's a program for about eight to ten individuals. We program or contract with private agencies to run a program. Just an interesting note about that program because I think this is indicative of some of the things we might be talking about here; we don't contract with anyone who cannot also provide some kind of activity for every resident that we place or that we deinstitutionalize. In the contract it says that in addition to a place to sleep and eat, they have to provide some way of getting these clients to and from different programs. They range from competitive employment to sheltered workshops to the developmental day care centers I mentioned before. The parents of this young lady, and note she is a twenty-two-year-old lady, have decided that what she needs most of all is to remain for the rest of her life in this state institution, because it's safe and it's quiet, it's lovely and it's far, far away from the city, and a few other such things. After thirty minutes of conversation, the chief of residential care explained about this national movement we have and about all the wonderful things that professionals have shown in the deinstitutionalization process. Just quite coincidentally, the legislator has a copy of our internal newspaper and there's an article in there by the superintendent of that very school. And he read it to me and in it quotes the superintendent as saying, "Communities are not adequately able to absorb the influx of such residents into the community." A constraint: the intra-agency disagreements that are going on.

The chief of evaluation had a better problem, I guess. This relates to the personnel regulations within bureaucracy. I'm not sure how I'm going to label this constraint. It seems as though the current examination for the entry level, direct-care workers jobs that we have are asking certain questions that very, very effectively eliminate certain minority people. In brief, certain people can never pass that test. Or to say it another way, the people that pass the test all look very much the same. I'm told the job specifications are written by my office. But we didn't write the examination, I tell them. But he said, "Yes, but you wrote the examples of duties." And so I sent for a copy of the examination and not only are the examples of duties and the examinations irrelevant, they bear no resemblance to each other. The questions that they ask are questions that I am sure I would flunk, and I don't know who wrote the test. But, here we are faced with a whole wide variety of citizen advocates that are saying, you know, never mind taking care of your clients, take care of society. We in society should also have a chance at helping you.

Off to another subject. Chapter 766, that's a favorite subject of mine. It's a new law. It's the Massachusetts law that unites us with a nationwide movement on behalf of special needy children. I was interested in my recent trip through a junior high school and it was a young man walking down the hall and I couldn't quite figure out what he was doing except I think he was doing what I did when I was in the seventh grade and that was procrastinating and trying not to get back to the room. And I said, "Could you direct me to the class for the mentally retarded?" And he said,

"Oh, do you mean the speshes?" You know, we don't have any mentally retarded kids anymore, we now have "speshes," and that was going to be an improvement over labeling children, I guess. I go off onto these tangents and then lose my place.

The Chief of Planning and Chief of Budget Management are meeting with the Department of Education representatives. They have the responsibility by this Chapter 766 of providing education for all special need children. The law says that the Department of Education will "establish and maintain an institution school department in every one of the state schools for the mentally retarded." The problem today is what does it mean to establish and maintain an educational program? Is that the teachers and the teacher aides? Does it mean the speech correctionist, the physical therapist, the psychologist, the recreation specialists and many more? I don't know. The Department of Mental Health says that if we take all those people that have something to do with the education needs of the youngster then we will be leaving the superintendent of the schools with being a high-class Ramada Inn in keeper.

The conversation in that particular case—the conversation went off on a tangent. That's my cue to get out. The tangent was, though, interestingly alluded to this morning a little bit by Mr. Thompson when he talked about the federal funding and the reimbursement policies. It seems as though if we move psychologists and speech therapists and physical therapists and recreation specialists and so forth out of the mental health rubric and into the education rubric, we might be cutting ourselves off of Title 19 or SSI or SSA or 4A or 89313 and all of those other numbers. And so a subcommittee has to be formed quickly to check on making sure that we don't lose out on federal funds. A constraint, with due respect to all of the "feds" that are here—a constraint to the delivery of our services.

It's sufficient to say that all of those things that I have just mentioned happened; they all went on before 9:20 in a working day. And when I got all the chiefs together and told them what I had said and shared what I was planning to do, they said be sure and add it's not so bad, because in another twelve hours after that time we'll all be home. We'll be resting comfortably, waiting for another day.

In a class action suit (*Mills vs. Board of Education in Washington, D.C.*) before a Federal District Court in September, 1971, the plaintiffs claimed their denial to an education was because of alleged mental, behavioral, physical or emotional handicaps or deficiencies. The school-age children had been denied placement in a publicly supported education program for substantial periods of time. It was pointed out that the handicapped children are "a voiceless and invisible minority who constitute perhaps the most vulnerable group in society. Those who need the most are denied the most. The direct care of front line people working with the severely multiply handicapped are often the least trained."

Bank-Mickelson, the man from Denmark, recently gave me his formula on how he would determine the

kind of a person we need to work with the severely multiply handicapped person. He was talking specifically about profoundly mentally retarded. He said, "Determine the mean IQ of the group of children; add to this the IQ of the staff member and the closer you get to 200 the better off you are." That means that if your clients have an IQ of 100, any one of us could fit the bill, but if the mean IQ of the group is 50, then we better start thinking a little more seriously about who we put in front of those people.

Back to the courts. A recent publication of HEW listed sixteen court cases under the title of "Right to Education." Numerous others were reported under other titles like "Right to Treatment," "Right to Protection," "Right to Peer Classification." During 1973, legislative advances in behalf of handicapped citizens were dramatic. I was going to list several of the notable ones. I should not leave this platform without listing at least one, Utah's Senate Bill 218, which I understand—which I don't understand. But I read the law. I thought I understood what the intention was and I was delighted since it mandates the local school boards will pick up the tab for the mentally retarded children who are now living in state institutions. And by the way, that worked wonders in my state, because local schools and local cities and towns realized that they could save money by bringing kids back into the community. And so it helped us in our deinstitutionalization processes. But the reason I said that I don't understand is that I read the other day in the *New York Times* that it's a wonderful law, Senate Bill 218, but that the legislature appropriated only half the money that's needed for that law. I don't know where the other half is going.

Sounds good. Legislative advances we can expect to really be of help to us, except one important thing that's bugging me. And that is that the courts and the legislators seem to be the primary impetus for change and it's not us. It's not the professionals.

The *Wall Street Journal*, December 18, 1973, featured an article. I received about eight or ten copies of that one article from friends all over the country that seemed to know this one bias of mine. And the headline was: Federal Court Order Brings Big Changes in Lives. And it goes on to talk about a southern hospital institution, where the federal court mandated changes and restored some dignity to the patients, to the clients. I think B. F. Skinner would probably have a reaction to one of the staff member's explanation in that southern hospital about his program. He said it was essentially a behavior modification program with a token economy. And the reporter said, what's that? And he said, well we send her out on errands to do things for us, and if she does them right we give her tokens, and if she saves up enough tokens, she goes out and buys things.

The German poet, Goethe, once said, "If you treat an individual as he is, he will stay as he is. If you treat him as if he were what he ought to be, he will become what he ought to be, and more, what he could be."

The constraints that I've identified, and I hope that I

will elaborate this afternoon on a dozen or so constraints, are basically related to traditions, with due respect to the Fiddlers on the Roof. They become fixed and very hard to break: to diagnosis, the art of which is somewhat unclear; our focus of attention which brings us great comfort in being able to assign labels to what's wrong; to satisfying money-givers and to compartmentalizing or fragmentizing services in some way; to inter- and intradisciplinary disagreements; to training models, etc. It occurred to me, after listing all these constraints, though, that practically 100 percent of them are not symptomatic of a disability. That is, they are not inherent in the child's severe, multiple handicap at all. They lie outside of the child. In some way they are imposed on that child. I'm optimistic, though, because I really believe that the disposition of those constraints is really within the control of professionals. Of you and I.

My chiefs are good people. They are able to deliver lots of good services, but their appointment books get in the way. Of course, appointment books are not inherently constraining. But the social handicaps that they present are. And I wonder, would severely, multiply handicapped children accuse us of being their appointment books? Thanks for listening.

THEMATIC STATEMENT ON OPTIONS FOR UNSERVED CHILDREN

BY DR. ELSIE HELSEL

Thank you, Bob. I'm not going to get trapped like the rest of these guys with all these notes coming up and not getting through my speech. I see you've probably got on your stag. The greatest collection of gabby people in the United States. We all write things down we have--Vance told us--no more than ten minutes, but we all run overtime. So, if you'll just get out your little folders, there's something in there called "Issues and Options for Severely and Multiply Handicapped Children." I'll try to get as far along through that as I can and what I don't get to when I get that little sign saying, you know, your time is up, then you can just read the rest of it all for yourself.

The other thing that I'm going to do is very quickly, whoever is going to show my six slides, get my children up here for you to see, because I hear us all worrying about are you really talking about the kids I'm talking about. Just leave Petunia up there for a little bit, and I want to get into my talk as I have written it.

I have chosen to talk about issues and options because I found I just couldn't separate them. And I'd like to--just for a minute--have you focus on what the issues, what some of the issues that I haven't heard mentioned this morning, are concerned with services for severely multiply handicapped, and ask yourself the question, do we really have options? Are we really ready? All the people in this room, to stand up in public in front of God and everybody and commit educational tax monies to a group of children who have little or no employment potential and who will have no way to pay society back for the investment in their education? Sorry about that, Paul, but even though I can see maybe one in a million getting into the employment field, a group of kids I'm talking about have no employment potential, and I don't want to fool anybody about it.

This little girl you see in front of you was a little girl found in one of the institutions. That child has absolutely no brain tissue at all, nothing. You can transilluminate her skull and nothing is there. She could--she was on tube feeding when we found her, she has no mouth closure, just an absolutely impossible child to manage. She's driving her family up a wall because she was screaming day and night. May we have the next slide on Petunia.

Here she is after we found out how to develop some procedures for Petunia. Teach her to suck and swallow, to be able to rest at night. Petunia has no employment potential, but I think Petunia has a right to education in terms of developing whatever skills she is able to have. That's one of the issues that I think we must face. Is the United States of America, the Congress, and the general public really committed to the Judaic-Christian ethic of the dignity and worth of every human being, including little Petunia? Or are we really still hung up on that work ethic? And are we willing, and do we have the guts to stand up to those people who are going to say to us when the bills begin to come in on the total cost of providing an education for this population, are we really willing to stand up to them and say yes, we are going to do it? No, we are not going to subscribe to euthanasia by

attrition, which is what you are going to propose to us: namely, just let them lie out there, keep them dry and warm and zonked out in bed for the rest of their lives. Because it's going to take real guts when the bill comes in to the taxpaying public and they find out what we're up to. These are difficult questions, but I think we'd better have some answers to them before we embark.

However, if you like challenges and you thrive on being on the cutting edge of the action, join with those of us with gray heads who came to this cause in the forties and fifties and thought we were developing services for this very group of children and we've been standing in the wings waiting all this time. We have lived through a lot of philosophies. One that was there when we came on the scene was if you've got a kid like this just forget it and hide it away somewhere. Don't bother us with it. Then we got a little more hopeful as we began to educate the public and get ourselves stirred together and we got into a philosophy of okay, let's screen these kids and segregate them. We'll do something for them, but keep them away from the rest of us. Now we hope we've gotten to a philosophy that says, okay, let's identify and help them, regardless of the cost and regardless of what they are going to contribute.

These are the children that I hope we are now concerned with and that we are trying to direct our attention to adequate programs for.

And now I'd like the other two kiddies that I brought with me so that I'm sure I'm talking about the children that you are talking about. Here's a little boy that we found in Central Colony. You'll say, my, isn't that nice--in an institution and he's got clothes on, shoes and everything. That's beautiful. That's really doing great for that kid. Excepting that he could have spent the rest of his life lying there, looking at the world and God only knows what it looks like from that position. Let me show you what can be done with a child like this with some of the techniques--and may we have the next picture of Joel? We found through one of our many team projects that a therapist told us if you just punch that little boy in the sternum you can inhibit some of those reflexes that are pulling his head back like that. And if you can keep pressure on him, and that is what the therapist is doing there in the next slide of Joel, notice that restraining strap around him, you can get Joel up into an upright position. He can get some functional use of his hands, he can relate to people. Joel now no longer lives in Central Colony in Wisconsin, but is out--that picture was made incidentally in Central Colony, but he no longer lives there. He is out in a group home. He is in a trainable program in the school system there. So, this is the kind of kid that I say is severely and multiply involved and that I hope we are directing attention to.

May I have the last little girl, and who told about some kids that you bring them in--oh, it was Dick--bring them into school, you can't get them into supportive equipment and right now all you can do is either lay them on a mat or litter. This is this kind of child who

has absolutely no muscle control at all. She could have spent her life looking at her navel

Next slide, please. Here she is when we finally bring to bear on this little girl all the knowledge and skills that we have in order to position her, in order to support her physically so that she is in a learning position. This little girl is going somewhere educationally. She may have employment potential if you can get her into the right kind of employment situation. I hope—may we have the lights, those are all the slides, I just wanted to see some of the kinds of kids I think—I hope we're directing our attention to.

This is an issue and it's a real issue and I think as you get into your groups you better resolve it. Because some of you are not thinking about kids like this. These are bottom-of-the-barrel kids, and until you address your attention to them you're not going to be satisfying my internal needs in any way, and I hope I'm not back here ten years from now addressing this same problem again.

Issue two that has been nibbled at by some of the other speakers are attitudes. Because I think they can arise to be the biggest constraints in this whole bag. Dick Sherr says he has some honest teachers who said, you know, I can't really teach that kind of kid. But there are a lot of educators out there who not only will be dishonest and not say that, they'll stay there and make life miserable for themselves and the kids. They'll go out and talk all over the community in addition and kind of wear your program down from within. There are professional attitudes that cannot relate to these kids and we've got a problem to know what to do with them. There are attitudinal problems among legislators who think these kids are not worth investing money in. You better get at it, find out what to do about it. For the first time down in Washington we are having trouble with our education for the handicapped. As Paul Thompson knows, we have trouble with our funding programs. We used to just go around and say to those guys, you don't want us to go back to your community and say you are not in favor of voting for legislation and money for the handicapped? And they'd say that big word that begins with A, certainly not. We don't want anybody to ever think of that and I'll vote for your bill. No more. You've seen vetoes come down the pike on every piece of legislation that we put through. We had two on vocational rehabilitation that used to pass unanimously. We couldn't even override the vetoes. It's a different day and age, and I think you have to realize if you're going to work for the handicapped, you've got to make a different kind of attack on the congressional level. The attitudes down there are really going to rise to haunt you.

And lastly, I think you better be sure you are working on the attitudes of other parents in your community. Because they've been willing to let our special education programs thrive so long as they didn't interfere with the educational programs for their own children. And when it comes to having to choose between whether we're going to field the football team and pay for the band up there—or are we going to use our money to edu-

cate these kinds of kids that we've been looking at—I think you might get some answers that don't make you feel too comfortable. So, I hope you are going to look at that.

And I would like to know, for a last issue, how strong our commitment really is. I picked up in Utah, in 1967, court ruling which looked like the same kind of thing that Pennsylvania got. So I'm thinking when I go to Utah in 1974, we're going to have a complete delivery system in place, surely. Do you? This is the kind of issue you better get looking at before you start to look at options.

Incidentally, don't feel badly, I don't know of any state that has all these beautiful things, good attitudes, lots of money, you know, and everything going for them. We're all in the same boat. But if you know what the problems are, I think you've a better chance of doing something about it.

Good, I'm to the part on options. I've shown you my kids, which is the most important thing, so I'm sure we're all off on the same foot. If you'll look at your sheets you'll find that in the options and issues group, we will be looking at options in three primary areas. We'll be looking at service delivery options: some you already know about, mainstreaming, self-contained classrooms, special schools, contractual relationships, but think about contracting with some new things, some new kinds of agencies that you haven't been contracting with before. Nonprofit ones you are pretty familiar with, but do you know there are some pretty good proprietary groups that are coming up and setting up programs for severely involved kids? These are profit-making groups. I don't care who does it, so long as it's done well and is of good quality. So don't pass up any options.

Home instruction for an area like we're in now where you've lots of roll problems I think may be something you may want to take a really strong look at and we'll be looking in our group at something that I found in Wisconsin—a portage-type home training, home teacher kind of delivery of service for kids where it's just impractical to try to bring them into groups. Obviously, I'd like them to come in for group instruction, but you can't always do that.

We will be looking at a different way of training manpower—options for manpower starting with the solo regular teacher, going up to a new kind of delivery system that we call the transdisciplinary teacher—a teacher who has kind of picked the brains of a group of professionals and put a program together for a child in a new way and then teaches the mother how to deliver the service. This is something that we'll be talking quite a bit about.

Options for funding—oh, I do want to read that part, because I think you just cannot think of taping all these costs on your school system and your school tax monies. I think you just cannot do it. The day is going to come when they're going to say no to you, and I'm saying to you school people, even if it means employing somebody in your shop to find out how

to access these other federal money streams, get with it. You can get your therapies paid for, sometimes your transportation paid for, your social services paid for, and I think you'd better learn how to play that game and access those monies in order to provide an adequate program for kids.

Now, the whole thing is a whale of a big job, but it sure looks like a fun job to me. And I think this conference gives us an opportunity to get our piece of the action, and I'm just delighted to be here.

Thank you.

THEMATIC STATEMENT ON WHAT IS RELEVANT EDUCATION

BY DR. LOUIS BROWN

I'm a teacher trainer, training teachers we hope will work with severely handicapped children. And I work at the University of Wisconsin in the Placement Center which is our version of a mental retardation center, or what used to be called a mental retardation center.

We spend most of our time in the Madison Public Schools, and I was very pleased to hear one of my colleagues say that she also worked at Central Colony at one time because we are intensively involved with Central Colony. What we are trying to do is produce people, turn out people, train people who can go into public school systems and function creatively, effectively with children who we refer to as severely handicapped.

Now, I think that because of the way we are set up in Madison, we get very few children that we get involved with that are multiply—what most people call multiply handicapped in the physical sense—in the sense of being deaf and blind. Most of the people we get when we go to Central Colony are behavior problems at one time in one form or other—self-stimulation, self-mutilation, this kind of thing. In public schools we get people who used to be called autistic, trainable, sub-trainables, pre-trainables, etc. Most of the physically handicapped in Madison attend a school that we are just starting to get into. I really felt that I should say that after hearing the second person before me say that she was vitally concerned with the developmental programs for the physically handicapped kids.

We use, essentially, a task analysis model in the training program. A substantial effort, as you might imagine, is directed toward securing people to work in these programs. As you probably know or are probably aware, the typical coeds at most universities don't come to the university with the intention of spending the rest of their professional lives with low-functioning children. Those people who do enroll in special education programs typically are interested in middle-class, emotionally disturbed kids, or mildly retarded kids. Or the big thing now, I guess, is to go into special learning disabilities. We have had and continue to have a substantial problem trying to recruit the kind of people that we feel would be effective with the kind of children we are working with. And I think people in this area are interested in setting up teacher training programs, so I think this might be a very relevant, very crucial point of discussion.

We have a reasonably novel way of doing it. We have an introductory course and a methods course. Well, this semester, for example, ninety-five people are enrolled in this course and all ninety-five are involved at Central-Wisconsin Colony or the Madison Area Association of Retarded Citizens or various other kinds of programs that relate to severely handicapped people. And what we try to do is to pick the people who are pretty good. Out of ninety-five we might find about thirty-five or forty who are doing something reasonable with the children that they are assigned to. And then what we try to do is essentially operate as college football coaches, and try to recruit them into what we feel is a program for these children.

But I think there are some very important, some very key issues here. We feel that there is an inverse relationship between the competencies, the intellectual abilities of the teachers and when compared to the development level of the children, the more handicapped the people, the more sophisticated the teacher may be.

We use a task analysis model and we're extremely precise. We structure classrooms, so we can avoid relating to typical behavior modification problems, management problems as much as possible, and focus on the development of academic skills. For those people concerned I would think we do very little with inferential data, most of the measurement systems we use in classrooms are related to trials to criteria, errors to criteria and that kind of thing. I realize that most of you people are thinking that we have severe management problems with these children and there is no doubt about it. We try to go the academic route, rather than the behavior modification route, and so we are very heavily into academic tasks—basic language, basic reading, basic math skills. We've made a substantial effort in the last five or six years in which we've attempted to develop an instructional program—reading materials, math materials, etc.

The essential thing is we're teacher trainers and we work in a public school. We try to recruit, select, and train people to work with low-functioning children.

Thank you.

THEMATIC STATEMENT ON PARENT EDUCATION AND THEIR ROLE

BY DR. PHILLIP ROOS

I'm going to start by talking about death. Most of us are going to face death sooner or later in ourselves as well as in our loved ones. When we face death in our loved ones, our society has developed a very palatable strategy for dealing with it. We go through a mourning reaction. We mourn. We grieve. There is an acute depression, and then we go happily on our way. When, however, a parent has a severely handicapped child, frequently that child symbolizes death. But it is an ongoing death, a continuing death to which there is often no end. It is not surprising, therefore, that Simon Olshansky refers to parents of retarded children as suffering chronic sorrow. And he describes this as a normal, not a pathological reaction.

To be sure, the parent of a severely handicapped child faces frustration every day of his life. But in addition to frustration, ladies and gentlemen, he faces some very deep and very meaningful existential conflicts. He is overwhelmed by feelings of helplessness, vulnerability, aloneness and the ultimate loss of immortality. It's not surprising, therefore, that the last twenty-five years have witnessed a new surge of voluntary associations composed primarily of parents of handicapped children.

The roles and functions of these associations have changed. Their early foci was to supply mutual support and to operate direct services for the children of the parents. Currently, the focus has changed to public information and education, to legislation, and the development of demonstration programs. And we are witnessing the emergence of new foci of activity. One of these is advocacy, citizen advocacy, agency advocacy, and as you have already heard, litigation. Parent associations have mounted suits in many of our states today. Finally, the setting of standards and the evaluation of programs.

With the emergence of these new roles for parents it is not surprising that there has been a veritable plethora of parent training programs. For example, we have today some viable training programs to teach parents to become citizen advocates. I brought with me a thrilling film which I will show the little work group this afternoon to illustrate the kind of training that is available in this arena.

There are training programs to train parents to become effective change agents, to evaluate knowledgeable programs and to articulate potently and meaningfully with administrators and professionals. There are currently programs available to train parents in the intricacies of legislative process, so they can go to the administrator and say, "Hey, baby, here's the way you get a hold of revenue sharing funds on the state and local level, to channel into programs for the handicapped."

Undoubtedly the greatest impact of training programs is in the area of training parents to be paraprofessionals. They are functioning as members of program teams. Everybody is overwhelmed by the lack of professionally trained personnel, so parents are moving into this arena with some degree of enthusiasm.

There is, of course, compelling evidence regarding the impact of early intervention as it impacts on later cognitive proficiency. There is considerable evidence that the modest teaching strategies are significantly related to their children's performance. We now have a wide spectrum of parent training technology and materials, curricula, manuals, films, cassettes, all this good stuff is readily available.

The approaches are primarily in two categories—cognitive and/or language development, and of course behavior modification. And research data indicate some very significant positive results from both of these approaches. We can point to an impressive number of successful programs in which parents handicapped children are functioning as paraprofessionals.

There have been some interesting expansions of the basic concept. For example, the training of foster parents, the training of mentally retarded persons to train younger mentally retarded persons. The training of parents to train other parents and so forth.

I do not propose, ladies and gentlemen, in our intensive little work sessions, to bombard you with any of this material. You will be given annotated bibliographies and summarized program descriptions in the work group. Well, parents are obviously ready to assume some key roles as trainers and educators, as planners, as evaluators, as advocates and as change agents. But we must face the fact, ladies and gentlemen, that the days of begging and pleading are past. Parents today are overwhelmed with feelings of impatience. They want action and they want it yesterday. We must realize, too, that there is a need for change in some of our professional attitudes towards parents. And there is a need for change in some parental attitudes for professionals. I'm convinced that opportunities must be created to foster a viable symbiosis among parents, professionals and other administrators.

I view this conference, and specifically the work sessions, as arenas—arenas in which we will create specific programs and practical strategies to capitalize on the forces that are existent in the societal matrix today and that will capitalize on the existing technology. If we succeed in creating these types of opportunities then I am convinced that the severely handicapped in our land will reap rich benefits.

~~_____~~ (workshop topic)

for Wednesday evening, 7:30 - 10:00 PM

NEED	BLOCKS (problems/contradictions)	GOALS (achievable objectives)
<p>What is needed to improve existing services or create new ones relative to topical area?</p> <p>(30 minutes)</p>	<p>What stands in the way of achieving a more effective delivery of services on topical area?</p> <p>(30 minutes)</p>	<p>What would be a set of four reasonable objectives or goals for the next twelve-month period? The needs and blocks may be re-articulated into goal statements.</p> <p>(1 hour)</p>
<p>Group brainstorm (list):</p> 	<p>Group brainstorm (list):</p> <p>Gestalt above into 4 Blocks:</p> <ol style="list-style-type: none"> 1. 2. 3. 4. 	<p>Group brainstorm (list):</p> <p>Gestalt above into 4 Goals:</p> <ol style="list-style-type: none"> Goal 1, Goal 2, Goal 3, Goal 4,

_____ (workshop topic)

for Thursday morning, 10:00 AM - 2:00 PM

[illegible]

—(workshop topic)

FORCES (to carry out program)	EVALUATION STRATEGIES (actions)	EVALUATION NEEDS (products)
Who are the individuals, groups, organizations, etc., who would be most suited to implement tactical plan? Or do the forces have to be created? (30 minutes)	What kind of evaluation is required to measure effectiveness of specific program? (45 minutes)	What kind of evaluation tools, models, plans, etc., are required to enable the evaluation strategies? (45 minutes)
Brainstorm (list): Relate above data to goals: Goal 1: Goal 2: Goal 3: Goal 4:	Brainstorm (list): Relate above data to goals: Goal 1: Goal 2: Goal 3: Goal 4:	Brainstorm (list): Relate above data to previous gestalt (goals/evaluation strategies) Goal 1 Goal 2 Goal 3 Goal 4.

State _____ Topic _____

Possible Agenda

1. General discussion on how to apply the wisdom of the conference to the needs of this state.
2. Would any of the goals or tactics need to be stated differently for this state?
3. Divide into 5 groups (by topic) and write a one-year timeline on how this state might begin to move concretely toward achieving stated goals. Timeline the tactics from previous workshop (Thursday AM) in a rational flow so that the goals from first workshop might be realized over a 12-month period. (1 hour)

SPRING (March-May)	SUMMER (June-August)	FALL (September-November)	WINTER (December-February)	GOALS
Tactics	Tactics	Tactics	Tactics	1.
				2.
				3.
				4.

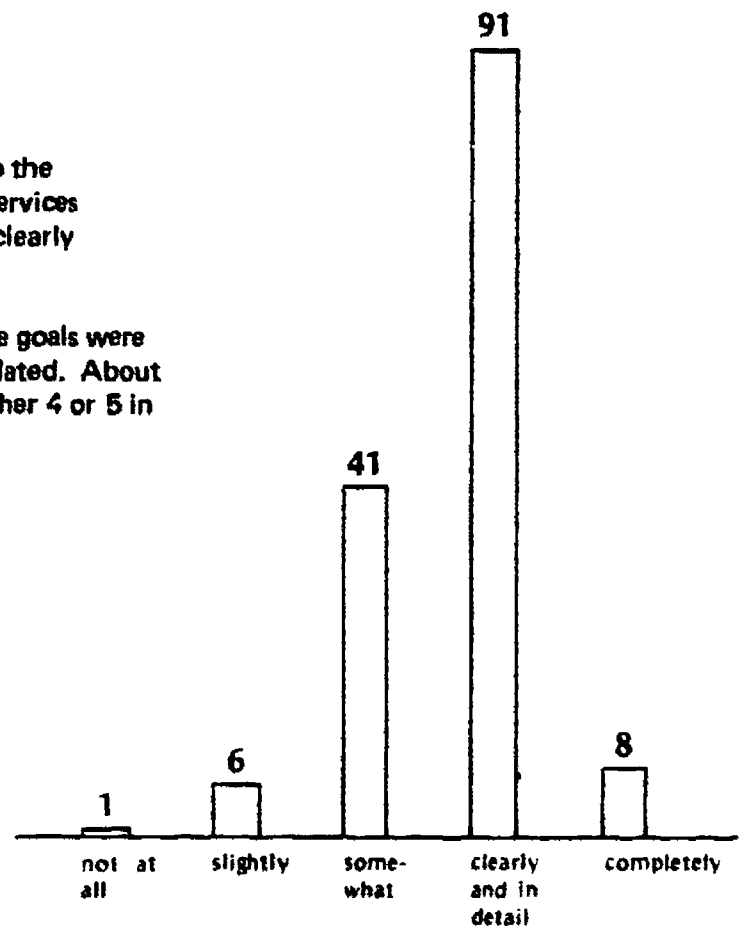
CONFERENCE EVALUATION

Introduction:

An evaluation questionnaire was distributed to participants at the close of the Friday morning workshops. The conference had a total of 257 participants, speakers and staff members during the 2½ day period. Of the total, it was hoped that the 215 actual workshop participants would respond to the evaluation. In actuality, 148 participants (or 70%) answered the questions. The other 30% can be accounted for by those who were out of the group at the time, those who had to leave early, or who simply forgot. The bar graphs below represent the number of responses to each category; they are reported in percentages. The last part of the evaluation is a synthesis of the last two questions of the evaluation. Of the 148 persons who responded, all of their comments are represented in as close to original form as possible.

Question 1: Were the issues relating to the provision of appropriate educational services to the severely multiply handicapped clearly articulated during this conference?

Comment: As Figure 1 shows, the goals were seen generally as fairly well articulated. About 2/3 of the participants marked either 4 or 5 in response to the question.

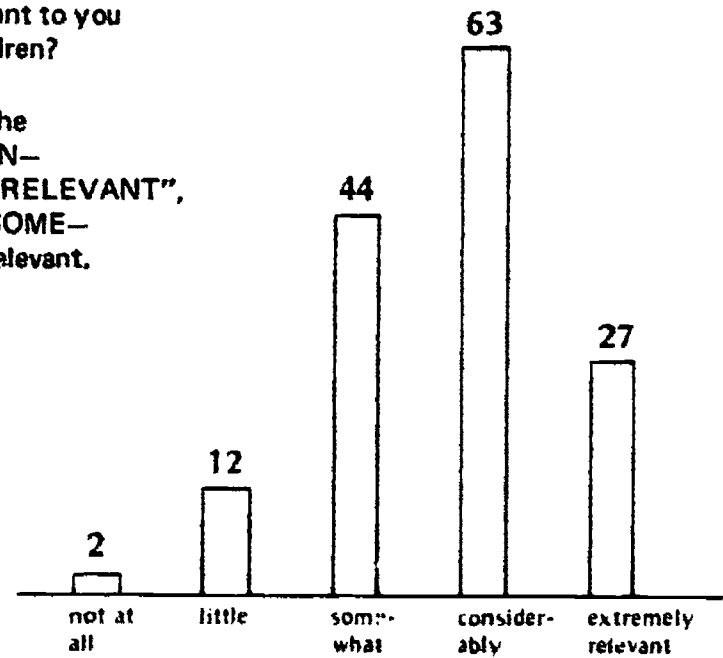


Question 2: Are you leaving the conference with practical first steps outlined for implementing or strengthening educational services to the severely multiply handicapped?

Comment: Eighty percent of the participants responded "Yes", 17% "No", and 3% made some other, somewhat ambivalent response (yes and no, partially, etc.).

Question 3: Was the conference relevant to you and your work with handicapped children?

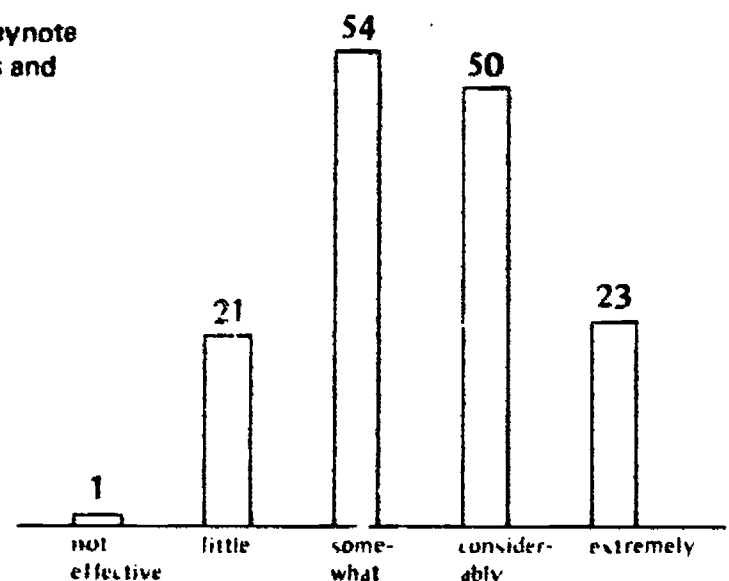
Comment: About three-fifths of the participants (61%) responded "CONSIDERABLY" or "EXTREMELY RELEVANT", the mean response was between "SOMEWHAT" and "CONSIDERABLY" relevant.



Question 4: Did you receive ample preconference information to prepare you for the conference?

Comment: This appears to be an area with potential for improvement for future conferences. Half of the participants responded "No", the other half "Yes".

Question 5: How effective were the keynote speakers in stimulating the participants and in keeping the conference in focus?



Question 6: Please circle the number corresponding to the grouping in which you participated.

Comment. The first column of numbers below indicates the number of respondents to evaluation in each workshop group. The second column is an estimate of how many participants were in each group, assuming that non-responders (early departures, forgetters, etc.) were proportionally distributed among the groups.

1. Systematic Delivery System (Richard Sherr)	24	35
2. Identification of Constraints (Albert Berkowitz)	26	38
3. Options for Unserved Children (Elsie Helsel)	30	43
4. What is Relevant Education (Louis Brown)	32	46
5. Parent Education and Their Role (Philip Roos)	<u>36</u>	<u>53</u>
Totals	148	215

Question 7: Keeping in mind the four times your topical group worked together, please respond to the following items:

- a. Did you have ample opportunity to express your views relating to the topic?

Comment: A very encouraging 90% of the respondents answered "Yes" to this question. Of the 10% who responded "No," many qualified their answer by such statements as "I'm not very talkative" or "It's impossible to discuss this topic enough."

- b. Were you presented with practical information that you could readily apply to your work situation?

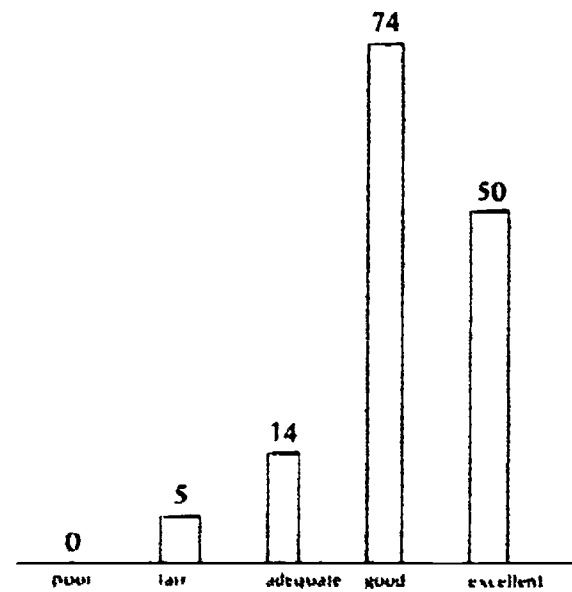
Comment: Precisely two-thirds of the respondents answered affirmatively. Although there were a number of conference participants without a work situation in which to apply the information (parents, for example), this appears to be an area of consideration for future workshops.

- c. Do you feel that the issues related to your topic and severely, multiply handicapped children were clearly identified and dealt with?

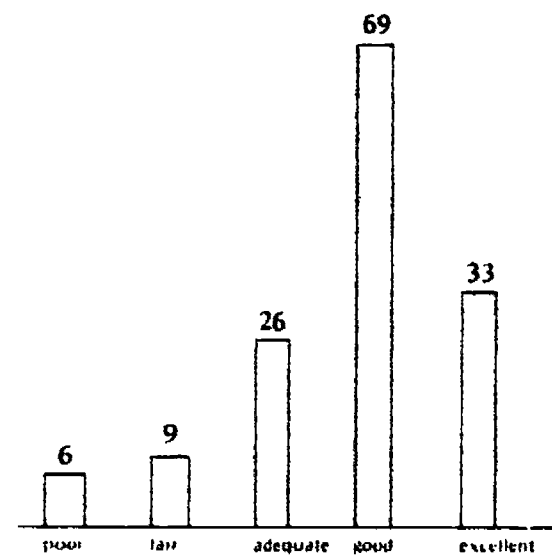
Comment: Fifty-three percent responded "Yes," 41% "Partially," and 6% "No."

Question 8: Please rate the following:

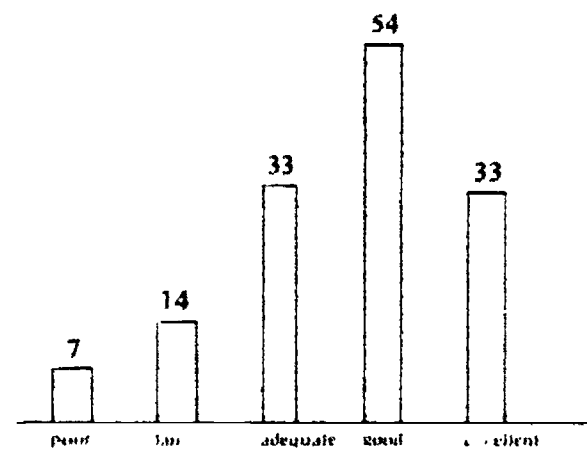
A. Conference facilities



B. Meals served at conference



C. Conference time scheduling



Synthesis of Conference Evaluation

Both positive and negative comments on conference evaluations gestalted into the two main categories of Format and Content, with minor differences in sub-categories, and no apparent distinguishing pattern among topical groups.

FORMAT

Question 9: Please list three things that you would change or do differently if a similar conference were to be planned again.

A. Scheduling : 101 responses.

Included under this heading were 51 calls for the elimination or earlier scheduling of evening workshop meetings; 17 calls for less time allotted to keynoters, usually with the suggestion that there be only one; 11 suggestions that the cocktail hour be scheduled at the end of the working day, not between sessions; and 7 requests for less rigid workshop assignment so that participants could float between topic groups. Also included were comments regarding more free time for interaction, earlier beginnings in the morning, structured sightseeing, and more adherence to time schedules.

B. More Small Group Process Interaction: 22 responses.

Included under this heading were calls for more expertise in group process on the part of topical resource leaders, for more facilitators other than the resource leaders, and for smaller groups. In short, improvement of the process, rather than deletion of it.

C. More State Focus: 20 responses.

Responses under this heading implied a positive attitude toward the state focus of the conference, but generally felt the focus to be inadequate. Included were calls for periodic state meetings throughout the conference, more time spent with state groups at the end of the conference, more input from the states as to specific state goals and needs before the conference, and workshop process forms built according to stated needs and goals of the states.

D. Accommodations: 10 responses.

Complaints here included inadequate breakfast service in the coffee shop, one description of the food as unpalatable, cramped coffee-break area, and a desire for a No Smoking rule.

Question 10: List three things that you would not change or do differently if a similar conference were to be planned again.

A. Scheduling, Organization, and Planning: 80 responses.

Of these responses, 28 specifically applauded the inclusion of evening workshops as adding to the commitment of participants and enabling goals to be reached. Other responses emphasized the excellent work of the conference coordinator and administrators, the completeness of pre-conference planning, the strict adherence to detail, the organization of working groups and breaks, the permanent assignment to specific topical groups, and the amount of time spent working.

-
- B. Small Group Process Interaction: 78 responses.**
Included under this heading were 25 statements of specific praise for the enablers and recorders of the small groups. 53 responses concerned the small group format in general, considering it thoroughly enjoyable as well as efficient, and crucial to the success of the conference. Appreciation was often expressed for the opportunity to interact with such a variety of people.
- C. Accommodations: 33 responses.**
Especially positive in this category was the convenience of housing the conference in the same hotel where participants roomed and ate; also included were positive comments on the food, the breaks, the cocktail hours, the locality, and the general atmosphere, friendliness, and hospitality of the conference.
- D. State Focus: 13 responses.**
Included here was appreciation for the specific invitations of state personnel, and the time allotted to state workshops.

CONTENT

Question 9: Please list three things that you would change or do differently if a similar conference were to be planned again.

- A. More Interdisciplinary Orientations: 47 responses.**
Under this heading were included calls for more opportunity to interchange with the total conference attendance as well as small topical groups, for more focus on educators by other professionals, and for more local professionals.
- B. More Practicality: 35 responses.**
Under this heading were included calls for more briefing of resource leaders as to specific geographical problems, more technical assistance to individual states for implementation, demonstrations, exposure to existing programs, visits to actual facilities, and more specific goals for the conference.
- C. More Clarity and Synthesis of Workshop Information: 33 responses.**
Under this heading were included calls for more and earlier pre-conference delineation of goals, workplan, and definitions of topics/issues, more structured clarification and demonstration of the model with concrete examples, and more opportunity for synthesis in large topical groups and in the total conference group.
- D. More Resource Leader Input: 10 responses.**
These responses usually meant more lecture time as opposed to the small group process. In one sense, these responses were actually positive evaluations of the resource leaders.

Question 10: List three things that you would not change or do differently if a similar conference were to be planned again.

- A. Leadership Input: 42 responses.**
Under this heading were included applause for the keynoters' speeches and informal dialogue, the resource leaders' thematic statements as well as their performance in topical groups.

- B. Quality of Coverage, Relevance, and Scope of Issues/Topics: 27 responses.**
Under this heading were grouped praise for the localized approach with inclusion of national ramifications, for the system of topical breakdown, for the relevance, scope, and general expertise experienced.
- C. Practical Goal Orientation: 10 responses.**
Included under this heading were specific statements of appreciation for a true "working conference," and the attempt to get at essentials and work toward a practical program goal, which could be carried back to the states.

The 16 Most Commonly Recorded Specific Statements

Question 9: Please list three things that you would change or do differently if a similar conference were to be planned again.

	Totals
1. Night meetings too much: start earlier, eliminate.	51
2. Have more small group work; smaller groups.	21
3. More and earlier pre-conference information on goals and relevant definitions.	20
4. Fewer keynoters with less time allotted.	17
5. More diversified, interdisciplinary approach: specifically parents, legislators, paraprofessionals, private agencies, and medical/health-care personnel.	15
6. More practical demonstration of the individual teaching of the severely multiply handicapped, with specific educators, visual aids, and visits to demonstration sites.	12
7. More time in state meetings--daily and at the end.	13
8. More concrete clarification of the model, with presentation of an example; more structured workgroups on the model; more precisely defined topic areas.	12
9. Cocktail hour after all working sessions over, not between sessions.	11
10. More input from resource leaders (lecture).	10
11. More provision for dissemination of complete information to all participants during the conference: more copying machines, recorders, blackboards, etc., with periodic dissemination of handouts from each topic group to all participants to avoid duplication	9
12. Opportunity to float between topic groups, or rotation by topic leaders.	7

13. More group process expertise in resource leaders.	6
14. More presentation of programs in existence and effective in other states; more interstate interchange, with demonstrations, slides, etc.	6
15. Have more educators, fewer bureaucrats in the keynoters; more utilization of challenging, local people.	6
16. Less orientation toward administrators, more toward service delivery people directly involved in dealing with the problems.	5

The 16 Most Commonly Recorded Specific Statements

Question 10: List three things that you would not change or do differently if a similar conference were to be planned again.

	Totals
1. Small group workshop process, and emphasis as a working conference.	41
2. Scheduling; especially the evening meetings, and time-lines.	28
3. Efficiency, and competence of all RMRRC enablers and recorders.	25
4. Organization, which was evident in the smooth operation of everything.	17
5. Accommodations: breaks, lunches, cocktails, service, etc.	18
6. Keynoters' input on federal level.	18
7. Competence of resource leaders.	14
8. Leadership and coordination of the conference.	13
9. State workshop time and focus.	13
10. Variety of people and professionals attending the conference.	10
11. Scope and relevance of subject matter, coverage of issues, integration of local and national concerns.	9
12. Thematic Statements.	7
13. Packaged materials received.	7
14. Working lunches.	7
15. Attempt to get to essentials and work toward practical goals.	7
16. Common workshop format sheet.	5

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Before, during and after the conference, each RMRRC staff member had several assignments that dealt with the conference. Major role responsibilities, including specific workshop assignments follow:

Barbara Ashford - Reception, registration, conference office
David Bradford - Message center, Systematic Delivery System, compilation of evaluation
Judy Ann Buffmire - Chairlady, Options for Unserved Children
Roberta Carter - What is Relevant Education, social hour
Shauna Edmond - Conference office, printing, copying materials
Vance Engleman - Conference coordinator, co-editor post-conference document
Donna Gough - Conference secretary, travel, pre-conference communications, post-conference document
Susan Harrison - What is Relevant Education, centerpieces and favors
Merrill Johnson - Tape recordings of keynoter and topical speakers, Options for the Unserved Children
Jan Mallett - Systematic Delivery System
Doris Mason - Options for the Unserved Children, post-conference document
Mack McCoulskey - What is Relevant Education
Ilene McKenna - Reception, registration
Jean Moore - Parent Education, editor post-conference document
Patricia Nelson - Media, Identification of Constraints
Frances Schweminger-Morse - Identification of Constraints, compilation of evaluation
Frank South - Systematic Delivery System
Gerry Ure - Reception, registration
Thomas Valeski - Photos of conference, Parent Education
Robert C. West - Options for the Unserved Children, social hour

Co-hosting the conference with the RMRRC staff was the faculty of the Department of Special Education, University of Utah. They are:

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